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The Role of Palliative Care in Severe and Persistent Mental Illness

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Abstract

This PhD dissertation arises from a research project investigating the suitability of palliative care approaches in the treatment of patients with severe and persistent mental illness. Specifically, the project was designed to initiate the discussion of alternative avenues of care for patients with a severe and persistent mental illness and an unlikely chance of ever recovering significantly. At the heart of this dissertation and as a basis for subsequent considerations lies a survey among German speaking psychiatrists in Switzerland.

The original research conducted throughout the PhD is organized by thematic focus, resulting in two paper series (sections). The first section is concerned with the acceptability and suitability of palliative care approaches for severely and persistently mentally ill patients. In the above-mentioned survey study, psychiatrists working in Switzerland were questioned regarding their attitudes towards palliative care approaches for and general concepts of severe and persistent mental illness. A number of 457 psychiatrists completed the survey (response rate 34.9 percent). Our findings revealed that the responding psychiatrists regard certain forms of severe and persistent mental illness as terminal, and believe that interventions with curative intent may in some cases be futile. Furthermore, a vast majority of the respondents believed that palliative care approaches can be suitable in the care of patients with severe and persistent mental illness. Drawing upon these findings, two subsequent papers conceptually examine the role of palliative care approaches in general, and palliative sedation specifically. Concerning the latter, it is argued that if one a) accepts that closeness to death is an unsuitable criterion for the initiation of palliative sedation and that b) intolerable suffering can result from both physical and non-physical symptoms, there is a weighty argument in favor of palliative sedation for the relief of intolerable suffering from non-physical symptoms. Such symptoms may potentially result from severe forms of treatment refractory mental disorders.

In the second section, the focus lies on the practice of (medical) assistance in dying in the context of severe and persistent mental illness. The first paper reports on items concerning (medical) assistance in dying (‘*Sterbehilfe’*) from the survey study. Psychiatrists were asked about their agreement with the practice and their willingness to actively support patients in their requests. A majority of respondents (about 50 percent) oppose (medical) aid in dying requests based on the suffering from a severe and persistent

mental illness. However, there was great variability between respondents, with a third of all respondents supporting the practice to some degree, and about a fifth of respondents remaining neutral. Willingness to support specific patients was higher in the specific case vignettes, whereas support was highest for the patient suffering from severe and enduring anorexia nervosa. Notable is the large variance in response patterns, impressively reflecting the lack of consensus regarding the controversial practice of (medical) assistance in dying despite Switzerland's liberal legal framework.

In the final chapter of this dissertation, the implications of these findings are discussed and integrated into a broader ethical debate. The dissertation concludes with an elaboration of potential underlying reasons for psychiatry's hesitancy in discussing end-of-life options in the context of severe and persistent mental illness, most notably preconceptions regarding the autonomy of (chronically) mentally ill patients and clashing professional obligations of psychiatrists with regard to patients who refuse further medical treatment.

Acknowledgments

I can think only of a few major crossroads throughout my life that are – looking back – easy to pinpoint. Having said this, I precisely remember when I decided to apply for this PhD position. Dating back to 2015, I was about to graduate as a clinical psychologist, knowing little about psychiatric ethics and the fundamental questions that have been on critical thinkers' minds since the times when the first psychiatric institutions were built. Yet, I have always been fascinated by the numerous particularities of psychiatry and am unbelievably grateful for being given time to explore them. Getting involved with this PhD project and simultaneously enrolling in the PhD program Biomedical Ethics and Law, was certainly one of my wiser "adult life decisions".

The past three years have been full of highly personal challenges and I will always remember my PhD as a time of conquering fears through simply *doing* things, without necessarily (always) being certain about them. Be it by presenting my controversial (read: contentious) work to a smart and critical audience of experienced physicians or by simply finding again and again this intrinsic motivation that kept me going at fast pace despite the infamous struggles virtually every PhD student encounters.

I must say, I am proud of myself! Yet, this wouldn't have been possible without the help of so many of you! First of all, I would like to thank my supervisors Manuel, Florian, Paul, and Nikola. I am thankful for having had competent scholars and clinicians by my side who were always right there to help me out when I was stuck and needed support. A big "thank you" goes to all the other amazing people who have been supporting me professionally in the past three years: Holger for lending me his tidy brain while putting together this thesis, as well as Valerie and Sam, and many others who have been sporadically involved in improving my work. To my great buddies at work and beyond – Daniel, Manya, Mirriam, Dominik, Ana, Matthias, Michelle and Daniela: Thanks for making my empty office so much more bearable.

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To new adventures!

Yours, Martina

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Abbreviations

CEBES	Checklist for the Ethical Evaluation of Empirical Studies that Don't Need Mandatory Authorization
FMH	Swiss Medical Association (*Foederatio Medicorum Helveticorum*)
HRA	Human Research Act
IRB	Institutional Review Board
(M)AID	(Medical) aid in dying
PC	Palliative care
PS	Palliative sedation
SAMS	Swiss Academy of Medical Sciences
SEAN	Severe and enduring anorexia nervosa
SPMI	Severe and persistent mental illness
SSPP	Swiss Society for Psychiatry and Psychotherapy
TRD	Treatment-resistant depression
WHO	World Health Organization

| INTRODUCTION

Setting the Scene

Outline

In 2010, the Swiss Federal Office of Public Health (FOPH) implemented the "National Strategy for Palliative Care 2010-2012." The FOPH has thus responded to the large gap in availability of and research on *palliative care* (PC) in Switzerland. Within the broader context of the National Strategy, the Swiss Academy of Medical Sciences (SAMS) issued medical-ethical guidelines and recommendations on PC, and implemented a funding program aiming at promoting the development and expansion of palliative care research in Switzerland. In its guidelines, the SAMS envisions an explicit role for PC in the context of mental health care. It states:

> Many psychiatric conditions can be chronic or are characterized by frequent relapses. In such cases palliative care, which is not aimed primarily at fighting the disease but aims at the best possible way of dealing with the symptoms or the disability, is all the more important. Often, this approach can enhance the quality of life and diminish the risk of suicide.

The guidelines go on to suggest that some patients with severe and persistent mental illness (SPMI) may benefit from PC approaches. Specifically, the patients who may benefit from PC approaches include those suffering from treatment refractory depression with repeated suicide attempts, severe schizophrenia, and poor quality of life (in the opinion of the patient); severest anorexia; and drug addiction. By broaching the issue of PC in the context of SPMI, the SAMS, perhaps unwittingly, made a progressive proposal. The lack (and relevance) of *end-of-life options* in mental health care, and for patients with SPMI specifically, is discussed fiercely in the medical-psychiatric community. Thus, this PhD project offered ideal conditions for systematically investigating how the complex needs of SPMI patients are perceived and addressed by contemporary psychiatric care.

The empirical project initiated and performed at the very beginning of this PhD project, a survey among psychiatrists in Switzerland, served as a cornerstone for further addressing questions around *autonomy* and *decision-making* as well as the currently available *care options* for SPMI.

The introduction provides the reader with necessary background information on SPMI patients, including concepts relevant to clinical decision-making for this patient group. It briefly touches upon the concept of *medical futility* and (*medical) assistance in*

dying ([M]AID) – two scenarios that have recently provoked an emotional and divisive debate within the medical and psychiatric community. The publications (*section I* with a focus on palliative care and *section II* with a focus on [M]AID) report on the findings from the above-mentioned survey among psychiatrists' attitudes toward goals of care and decision-making for patients suffering from severe and persistent mental illness. Here, a focus lies on the acceptability of *palliative care approaches* and the attitudes toward the practice of (M)AID for patients with severe and persistent mental illness. The subsequent papers conceptually approach the potential role PC may have in mental health care. In the third part of this thesis, I aim at integrating the original research into a broader ethical debate. I present my observations regarding the understanding of autonomy in the context of SPMI and the professional obligations guiding clinicians concerned with the care of SPMI. Finally, I discuss potential clinical implications of my work, and possible future research domains.

Why Palliative Care?

It is an inconvenient truth that available treatments in mental healthcare have limited efficacy, and the management of patients with persisting symptoms despite adequate treatment trials remains a major public health challenge. For example, more than a fifth of all patients diagnosed with major depressive disorder fail to respond to several steps of adequate treatment trials (Rush et al., 2006). For schizophrenic disorders, the outcome is equally poor: as many as 10 to 30 percent (depending on definition of treatment resistance) of all patients have little or no response to antipsychotic treatment and another third of all patients continue to experience positive and/or negative symptoms that effect their lives profoundly (Hasan et al., 2012). Mortality rates for patients with anorexia nervosa are dramatically elevated, with crude mortality rates of 5 to 6 percent (Arcelus, Mitchell, Wales, & Nielsen, 2011). Furthermore, a substantial number of SPMI patients die from suicide, sometimes after being invested in therapy for many years. The recognition that current psychiatric services still fail to significantly improve the lives of many of their patients, let alone cure them, has led some authors to the proposal of exploring alternative avenues of care that primarily focus on quality of life and relief of suffering. One of these proposed approaches is the expansion of palliative care approaches to mental health services (Berk et al., 2012; Trachsel, Irwin, Biller-Andorno, Hoff, & Riese, 2016b).

The field of PC has undergone a major transformation in the past four decades. Originating from the hospice movement in the 1960s (Clark, 2007), PC for a long time focused on cancer patients. This narrow scope is prominently represented in the first WHO definition of PC in 1990:

> The active total care of patients whose disease is not responsive to curative treatment. Control of pain, other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best possible quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with anticancer treatment.

Since 1990, the WHO has continued to be essentially involved in the evolution of PC, and has revised its definition several times. According to the most recent WHO definition, PC is:

> An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

Most importantly, the WHO has extended the clinical application of PC to *life-threatening illness*, rather than limiting it to patients with a cancer diagnosis (World Health Organization (WHO) 2014., 2014). It has thus recognized the potential use of PC for diseases other than cancer. Nowadays, common medical conditions of people requiring palliative care include serious physical illness such as HIV/AIDS, motor neuron disease, muscular dystrophy, multiple sclerosis, liver failure, renal failure, Alzheimer's disease and other dementias, spinal cord injuries, and, most recently, mental disorders (Berk et al., 2012; Pastrana, Jünger, Ostgathe, Elsner, & Radbruch, 2008). This expansion of palliative care approaches has not come without criticism, and the lack of common language and the heterogeneity of the PC population is argued to hinder research on PC as well as its implementation and best practices (Currow, Wheeler, Glare, Kaasa, & Abernethy, 2009).

Palliative Care within Mental Health

Palliative psychiatry is the term suggested by some authors to describe an approach within psychiatry that primarily aims at improving quality of life through harm reduction rather than *questionable* (either because highly burdensome or most likely

ineffective) psychiatric intervention (Trachsel et al., 2016b). However, the fuzziness regarding the definition of PC and disagreement regarding its clinical scope (Hanratty et al., 2006; Payne et al., 2002) have previously affected the acceptance of the term *palliative* within a psychiatric context (McGorry, Berk, Berk, & Goldstone, 2012; Trauer, 2012). There is no consensus on when in the course of a disease PC should be implemented, whether it is compatible with curative treatment, or who should get it. In the psychiatric context, it has been suggested by various scholars that a palliative approach be implemented at later stages of the illness for patients with persistent mental illness severely affecting their quality of life and daily functioning (Berk, Singh, & Kapczinski, 2008; Trachsel et al., 2016b; Trachsel, Irwin, Biller-Andorno, Hoff, & Riese, 2016a; Trauer, 2012).

It has been argued that a palliative care approach within mental health essentially is about compassionate care and practice and that the provision of palliative mental health care will require a realignment of some fundamental ethical assumptions that have guided mental health care to date (Geppert, 2014; see Table 1 below).

Table 1

Comparison of Mental Health Care and Palliative Care Ethical Assumptions

Assumption	**Mental health care (traditional sense)**	**Palliative care**
Orientation	Biobehavioral	Humanistic
Objectives	Cure disease Control symptoms	Improve quality of life Relieve suffering
Focus	Individual person	Person, family, community
Autonomy	Constraint and compulsion if needed to prevent harm	Choice and flexibility even if reduces length of life

Note. Adapted from Geppert, C. M. A. (2014). Overcoming ethical dilemmas. In D. B. Cooper & J. Cooper (Eds.), *Palliative care within mental health* (1st ed., pp. 19–29). London: Radcliffe.

In the light of these considerations, the conceptual similarities between palliative care within mental health and the r*ecovery model* is evident. Indeed, reservations regarding the implementation of a palliative care approach were not infrequently based

on the fear that palliative care undermines or denies the importance and impact of the recovery model. Furthermore, it was argued that endorsing PC for SPMI is fundamentally incompatible with the principles of the recovery model, such as hope, empowerment, and personal growth. Subsequently, the potentially delicate and unwanted competitive situation between the recovery model and PC within mental health will be considered in more detail.

A note on compatibility of palliative care and the recovery model. It is important to stress that PC as it is understood here, is not only compatible with a recovery-oriented approach but also shares some of the core principles with the recovery model. The second basic assumption underlying all further reflections in this thesis is that starting a discussion about the reality of irremediableness/ongoing suffering and fatality in SPMI does not equal fueling hopelessness and/or campaigning for a pessimistic approach in the care of SPMI. It can be said with safe conscience that the (initially) user-driven recovery model is among the major positive transformation mental health care has undergone in the past few years, and probably the first time the lived experience of SPMI patients is put at the center of psychiatric care. It is not the intention of this work to deny these achievements or suggest replacing recovery-oriented services with PC. Instead, it is aimed at drawing attention to the small group of very severely mentally ill patients, who are potentially in need of additional layers of support. Furthermore, it is at least questionable whether really "everyone with mental illness can recover" and we believe that for a small number of patients, *personal recovery* in the sense of regaining "a way of living that is satisfying, hopeful, and contributing […] even with limitations caused by the illness" and developing "[…] new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness" (Roberts & Wolfson, 2004, p. 39) may not be possible. For this group of patients, an additional layer of support may be helpful.

Identifying the Cohort

The clinical staging model in psychiatry. Despite its great clinical importance, there is no universal agreement on the definition of treatment refractoriness for any of the major diagnostic classes of mental disorders (Kane & Correll, 2016), rendering scientific discussion and clinical translation of research particularly difficult (Conway, George, & Sackeim, 2016; Howes et al., 2016). A relatively new model of describing the progressive nature of mental disorders is the *clinical staging model*. In various medical specialties, clinical staging models are utilized to classify seriously ill patients in order to determine

adequate treatment regimens (Amin et al., 2017). In psychiatry, the clinical staging model is comparatively new, but is rapidly gaining momentum. A valid staging model is intended to allow classification of patients according to their resistance to treatment and inform treatment selection accordingly, and therefore improve clinical management of the patient (Ruhé, van Rooijen, Spijker, Peeters, & Schene, 2012). The model is thought to have the potential to overcome diagnostic boundaries and enhance practical value through high clinical utility (McGorry, Hickie, Yung, Pantelis, & Jackson, 2006; Scott et al., 2013). An example of suggested criteria for three major SPMIs is given in Table 2. Depending on the staging models, different variables are included in defining the stage. For example, many staging models for depression use the number of adequate antidepressant trials in their definitions, and some also include other treatment approaches such as psychotherapy or ECT (Ruhé et al., 2012). Because the clinical staging model is less rigid in its definition of stages and allows for heterologous clinicopathological scenarios, it has the potential to facilitate identification of patients with chronic and unremitting disease and an enhanced risk of dying prematurely.

Table 2

Proposals of Clinical Staging for Schizophrenia, Unipolar Depression, and Anorexia Nervosa

Stage	Schizophrenia	Unipolar depression	Anorexia nervosa
1	prodromal phase with deterioration of functioning	prodromal phase a) no depressive symptoms (generalized anxiety, irritability, anhedonia, sleep disorders) with mild functional change or decline b) mood symptoms (sad mood, subsyndromal depression)	prodromal phase: "uneasiness and fullness" after eating, reduction of food intake, choice of "safe" food
2	acute manifestations	major depressive episode	acute manifestations: severe restriction, increased activity levels, complete denial of the illness, growing attention to body weight/shape/size, social impairment

3	residual phase	residual phase a) no depressive symptoms (sleep disturbance, generalized anxiety, irritability, anorexia, impaired libido) b) mood symptoms (depressed mood, guilt, hopelessness) c) dysthymia	residual phase
4	chronic phase (in attenuated or persistent form)	a) recurrent depression b) double depression (co-existence of major depressive disorder and persistent depressive disorder/dysthymia)	chronic (in attenuated or persistent form): extreme emaciation, laborious exercise and "general debility"; risk of co-occurrence of other psychiatric disorder (e.g., alcohol use disorder)
5		chronic major depressive episode	

Note. Adapted from Cosci and Fava (2013)

Severe and persistent mental illness. Over the last two decades, considerable resources have been devoted toward identifying patients in the early stages (stages 1 and 2 in Table 2) of mental disorders in order to develop effective strategies for prevention, and delayed or inadequate treatment is recognized as a major contributor to chronic and severe courses of mental illnesses. While early diagnosis is of great value for preventing potentially severe and persistent mental illnesses, the risk of neglecting patients with established illnesses has also been identified (McGorry, 2005). With a clear weight on the earlier stages and one-sided distribution of clinical and research resources, care options for patients in later stages remain limited (Berk et al., 2008). Patients who meet the criteria for stages 4 and 5 typically have well-established treatment resistance and present with persisting clinical symptoms that have a major impact on their quality of life and functioning (McGorry et al., 2012). Many of them have been ill for years, and have survived one or several suicide attempts. They have a very low probability of benefiting from additional pharmacological treatment (Rush et al., 2006) and are disproportionally prone to receiving care that is experimental, highly intrusive, burdensome, or in other ways not in line with their personal values (Berk et al., 2008). In addition, their ability to

decide for a certain treatment option is frequently *questioned* due to a persisting presumption of impaired decisional capacity and (acute or chronic) risk of death (Campbell & Aulisio, 2012). Unsurprisingly, providing care for patients with treatment-refractory illness may prompt helplessness in providers and is therefore frustrating and unattractive (Lauber, Nordt, Braunschweig, & Rössler, 2006; Minkoff, 1987), especially among psychiatrists themselves (Lauber et al., 2006).

Recent development of social policy regarding the expansion of the practice of (M)AID to such patients with unremitting psychiatric illness has provoked a heated debate regarding differentiation between mental and physical illness, competency, and questions of irremediableness and futility in severely and persistently mentally ill patients with a death wish. Before further elaborations on the topic are presented, three case vignettes depicting stage 4/5 SPMI patients are presented in the following section.

Introduction to the Case Vignettes

The survey among psychiatrists in Switzerland consisted of both general conceptual questions surrounding the topic of SPMI and questions directly related to specific clinical situations presented in the form of case vignettes. All case vignettes were taken from previously published material and were minimally adapted to suit the format of the survey. In this section, the case vignettes are briefly discussed in order to allow a more comprehensive understanding of the target patient group relevant to this project.

Case 1: Anorexia Nervosa

Originally published in Trachsel, Wild, Biller-Andorno, & Krones (2015)

37-year-old female with anorexia nervosa, onset at age 11

Symptoms: general muscle weakness; loss of bone density; amenorrhea; current weight 24kg/52 lbs; BMI 9.5 kg/m2; no recent weight gain or stabilization; no acute danger of dying, as her body is adapted to being underweight.

The patient underwent 10 previous inpatient treatments (in both somatic and psychiatric hospitals), three of which were in specialized psychiatric institutions. Throughout the course of the disease, different intensive psychotherapies have been tried, without success. During hospitalizations, the patient underwent several artificial re-feedings, sometimes under sedation. The patient now refuses artificial re-feeding and treatment. She states that, for years, her life has been focused exclusively on trying to overcome her anorexia, leaving her without friends or hobbies. She suffers from the physical symptoms, including general muscle weakness and loss in bone density, saying that she would rather die than undergo further treatment, and wishes to be

left in peace. She does not want to be forced into eating anymore. Two experts have declared that the patient has decision-making capacity to refuse further treatment, with consequent risk of dying.

The patient presented in case one suffers from a very severe and enduring form of anorexia nervosa (SEAN). As mentioned above, patients diagnosed with anorexia nervosa have significantly elevated mortality rates (Arcelus et al., 2011) and full recovery is achieved in less than 50 percent of all patients (Steinhausen, 2002; Zipfel, Löwe, Reas, Deter, & Herzog, 2000). Lifetime variables predictive of mortality are previous suicide attempts and longer duration of the eating disorder (Huas et al., 2011; Keel et al., 2003). Patients who suffer from a lifetime of severe illness often pose a major challenge to their healthcare team (Strober, 2004), and many patients question the value of offered treatments at some point. Due to the life-threatening nature of their illness, patients with AN are particularly prone to non-consensual treatment scenarios (e.g., coercive measures such as forced tube-feeding). Additionally, their treatment refusal is said to be qualitatively different from treatment-resistance because available and efficacious treatment (nutrition) is *refused* rather than inefficient (Geppert, 2015). There has been an extensive discussion of decisional capacity in patients with severe and enduring AN, as starvation and malnutrition is known to cause structural abnormalities in the brain, likely negatively affecting cognitive abilities (Katzman, Christensen, Young, & Zipursky, 2001).

Case 2: Schizophrenia

Originally published in Brenner et al. (1990)

33-year-old male with schizophrenia, onset at age 17, no significant comorbidities

Positive symptoms: auditory and visual hallucinations, persecutory delusions. Negative symptoms: apathy, social withdrawal, poverty of speech (all rated severe).

Despite long-lasting, high-dose pharmacological treatment (several atypical neuroleptics, haloperidol, clozapine, and combinations of these), as well as electro-convulsive therapy, the patient has never been free from positive or negative symptoms. Multiple psychotherapies of various kinds have also failed to stabilize the patient or to improve his quality of life. He does not wish to continue assertive community treatment because he feels it is too intrusive. While the positive symptoms were more dominant in the first years following initial diagnosis, he went on to develop severe negative symptoms, as well as aggression and self-injurious behavior such as

burning himself with cigarettes. The negative symptoms and his strong functional deficits are exacerbated by chronic unemployment and inability to live independently, and the patient has no family system. His persisting illness has left him completely isolated, with no social contacts and no hobbies or interests. Two experts have declared that he possesses decision-making capacity in respect of his illness and its treatment.

The patient described in case two suffers from a severe and persistent form of schizophrenia. Although this patient does not have an immediate risk of dying, his life expectancy is likely negatively affected by his persisting mental disorder, and the development of comorbidities that affect his health in the future is likely. The patient's (self-assessed) quality of life is very low and he feels overwhelmed by potentially beneficial but intrusive attempts at engaging him in treatment. The patients would like to "be left alone," which would potentially lead to an aggravation of symptoms and repeated involuntary admissions (including phases of *non-consensual treatment* if the patient loses his decision-making capacity as a result of not engaging in treatment [e.g. not taking his antipsychotic medication]). People with schizophrenia are typically faced with difficulties in accessing health care, employment, and educational opportunities. Treatment is often focused on antipsychotics and there is a tendency for providers to *convince* patients to take antipsychotic medication despite recent doubts about the efficacy and effectiveness of clozapine in later stages of schizophrenia (Kane & Correll, 2016).

Case 3: Major Depressive Disorder

Originally published in Baweja & Singareddy (2013)

40-year-old male with major depressive disorder, no significant comorbidities

Symptoms: energy loss, insomnia, fatigue, persistent suicidal ideation over 20 years, current acute and concrete suicidal intent.

The patient underwent different intensive, evidence-based, long-term psychotherapies, including specialized treatment approaches such as CBASP and IPT. His depression was not improved either by psychotherapy alone or in combination with adequate treatment trials of antidepressants (selective serotonin reuptake inhibitors, tricyclic antidepressants, venlafaxine, augmentation with lithium, and antipsychotic medications [quetiapine and aripiprazole]). The patient experienced significant adverse effects with several of the medications. Exhausted and as a last resort, he decided to undergo electro-convulsive therapy. However, maintenance electro- convulsive therapy proved equally ineffective in preventing the reappearance of suicidal ideation; indeed, the symptoms worsened. The patient experiences severe hopelessness and states that his quality of

life is very poor, that he doesn't want to deal with his illness anymore, and that he plans to commit suicide in the near future. Two experts have declared that he possesses decision-making capacity regarding his illness and its treatment.

The patient described in case three suffers from what is commonly called treatment-resistant depression (TRD). Ethical considerations regarding access to (medical) assistance in dying for psychiatric patients has been dominated by this patient group (Schuklenk & van de Vathorst, 2015a). This patient expresses a wish to die because the suffering from the depression has become unbearable. Although there is no imminent suicide risk, forms of such *autonomous/rational suicide* pose a major challenge to psychiatry, with its uncompromising focus on suicide prevention. Patients with TRD who refuse to undergo potentially helpful yet highly intrusive and possibly experimental treatment such as deep brain stimulation paradigmatically illustrate ethical conflicts frequently occurring in the treatment of patients with SPMI: the respect for patient autonomy and the principle of beneficence.

Ethical Challenges in Caring for SPMI Patients

Although the patients presented in the case vignettes above present with different complex clinical pictures, they have a number of things in common: All three patients report very low quality of life because of their SPMI and wish (to different degrees) to stop further intrusive treatment because, up to this point, treatment has not only been unsuccessful for them, but also proved severely burdening at times. They have now arrived at an "enough is enough, already" state of mind (Yager, 2015). Moreover, all three patients have an elevated risk of death, either as a direct result of their disease (e.g., cardiac arrest); indirectly, as a result of severe comorbidities or adverse effects of psychopharmacological treatment they have undergone (e.g., cardiovascular disease); or through suicide. Despite the fact that most clinicians (and scholars) would acknowledge the clinical reality of SPMI patients such as the ones described in the vignettes, there is little guidance on how to best balance patient *autonomy* (an expressed desire "to be left alone," to stop potentially helpful but intrusive treatment) with the *principle of beneficence* in such cases. The following section will briefly introduce core ethical concepts that are relevant when thinking about treatment decisions of SPMI patients. An in-depth ethical analysis, considering both the empirical results gathered in the survey as

well as conceptual deliberations during this PhD project, can be found later on in the general discussion.

Autonomy and Beneficence: A Special Area of Tension in Psychiatry

The respect for personal autonomy is rooted in the liberal tradition of individual freedom and choice. Respecting an autonomous decision "is to recognize with due appreciation that person's capacities and perspective, including his or her right to hold certain views, to make certain choices, and to take certain actions based on personal values and beliefs" (Beauchamp, 2009, p. 34) In contemporary medical ethics, patient autonomy has been a guiding principle. Many – if not most – ethical issues in psychiatry arise when a person's (potentially) autonomous wish is overridden (Beauchamp, 2009). Such *paternalistic* inferences are justified on the grounds of *beneficence* or *non-maleficence*. Examples of paternalism include involuntary commitment to institutions, compulsory psychiatric care, or interventions to stop a planned suicide (Beauchamp, 2009). There is broad consensus in research and in clinical practice that in some circumstances, beneficent *coercion* is justified, namely when patients lack decisional capacity (*Urteilsfähigkeit*) and make choices that are likely to cause them harm. However, such coercive interventions are more frequent in psychiatry than in any other medical subspecialty. Several characteristics of SPMI patients may contribute to the high prevalence of coercive interventions.

Firstly, clinical decision-making may be challenged by fluctuating cognitive abilities of the patients and the clinicians' personal values and attitudes (Hermann, Trachsel, & Biller-Andorno, 2015). Empirical evidence that SPMI patients are *per se* incapable of making decisions, however, is lacking. Nevertheless, an initial doubt about decisional capacity is more the rule than the exception to it. After all, decision-making capacity is a normative concept that should be free from personal values and norms of the assessors (Hermann, 2015).

Several other aspects, though related to the concept of decision-making capacity, are relevant when thinking about treatment decisions for SPMI patients. To what extent, for example, can chronically mentally ill patients still be *authentic?* Specifically, how is an articulated wish of a patient to be evaluated if it is potentially affected by a cognitive distortion – but this distortion is immovable despite treatment? In other words, what if chronicity renders relying on a past *authentic self* impossible, and poor prognosis makes a *future authentic self* highly unlikely (Dembo, 2013)? In cases of prolonged mental

illness may the illness itself be a part of, or perceived to be a part of, the patient's personality (Johansson et al., 2011)?

Secondly, despite danger to self and suicidal tendencies (*Suizidalität*) being one of psychiatry's core topics, the ethical implications of chronic life-threatening mental illness are not systematically discussed outside the context of *suicide prevention* and *(M)AID* practices (see next section). Self-endangerment typically establishes a basis for *involuntary admission* (and treatment – depending on the legislation). Seemingly the only context in which the issue of a potentially fatal outcome in psychiatry by omission of further treatment has been discussed is in case of a *medical futility* and *(M)AID*.

Terminating Care based on Futility Judgment

A prominent definition of medical futility distinguishes between a quantitative and a qualitative approach (Schneiderman, 1990). Quantitative futility, according to Schneiderman, occurs when "physicians conclude (either through personal experience, experiences shared with colleagues, or consideration of reported empiric data) that in the last 100 cases, a medical treatment has been useless." Qualitatively futile, on the other hand, is any treatment that fails to be beneficial to the patient, e.g., by merely preserving unconsciousness (Schneiderman, 1990). Based on these definitions, so the argument goes, physicians have no obligation to continue treatment. In a pioneering paper, Lopez, Yager, and Feinstein (2015) have argued that medical futility might be equally applied to some very severe cases of mental illness. Opponents object that the concept of futility is unsuitable in the context of psychiatric disorders, pointing to high prognostic uncertainty. For example, a renowned clinician and bioethicist has argued that, "when writers refer to 'end stage' AN, they cannot point to a well-established temporal gradient of psychopathology that would allow one to say confidently, 'This is the end of the process.'" The expert further mentions the effects a futility judgment might have on attitudes and behaviors of caregivers (e.g., demoralization), and argues that futility judgments would mainly reflect the physician's frustration and feeling of impotence when treating patients with refractory AN (Pies, 2015). Other authors point to the risk that lies in lumping together treatment refractoriness and treatment refusal, and the possibility that the latter might potentially be rooted in pathological denial of the illness (Geppert, 2015). Maybe partly as a result of a "terminology war," consensus in this matter was never reached, despite its increasing relevance. In the wake of the global liberalization of the practice of (medical) aid in dying, questions surrounding futility of treatment for some

patients with a lifelong history of SPMI, however, have regained topicality: Under which circumstances (if ever) should patients with SPMI have a right to seek assistance in dying?

(Medical) Assistance in Dying

The question whether the practice of (medical) assistance in dying ([M]AID)[1] should ever be available for severely mentally ill patients is one of the most fiercely debated topics in contemporary psychiatry ethics. Switzerland is among the few countries where patients with SPMI can legally request assistance in dying. As a result, a small but increasing (Steck, Junker, & Zwahlen, 2018) number of SPMI patients die every year with the help of right-to-die organizations (RTDOs). Yet, as the empirical work within this PhD project and previous investigation have shown, only a minority of the psychiatric community in Switzerland is supportive of this practice (Brauer, Bolliger, & Strub, 2015). Psychiatry is an extraordinary area of tension when it comes to respecting autonomous wishes of patients potentially leading to their deaths. Indeed, there is a longstanding public health priority of *preventing* suicide rather than *assisting* it (WHO, 2000). This is not surprising, since evidence suggests that more than 85 percent of persons who die by suicide have a diagnosable mental illness (Arsenault-Lapierre, Kim, & Turecki, 2004; Nock, Hwang, Sampson, & Kessler, 2010). The predominant viewpoint in psychiatry is therefore that suicide is pathological and must be prevented. In contrast to severely physically ill patients, patients with severe mental illness are generally excluded from what has been called a *rational suicide* (Hewitt, 2013). Reservations over the capacity of SPMI patients with regard to (M)AID, as well as the high risk of false positives due to prognostic and diagnostic uncertainty, have led a majority of the psychiatrists to fiercely reject (M)AID based on the suffering from an SPMI. However, there seems to be an unspoken consensus that at least some patients suffering from SPMIs such as TRD may still be competent to make their own treatment decisions (Schuklenk & van de Vathorst, 2015b). By acknowledging that such patients may sometimes suffer as unbearably as severely physically ill patients, a rather strong argument for allowing these patients to

[1] There is no consensus on terminology regarding assisted suicide. In this thesis, the term *(medical) assistance in dying* (*[M]AID*) is used, while in the published chapters, the originally chosen terms are left unchanged.

modify treatment in a life-limiting manner or request assisted suicide is made. Proponents therefore argue that excluding patients with mental illness from the rational suicide debate is unfairly discriminating (Schuklenk, 2015). But how, if at all, should psychiatrists interact with patients who wish to end their lives, even if death other than by suicide (unlike in, for example, some SEAN patients) is not imminent?

Research Objectives

In light of the considerations above, the original research performed during this PhD project aimed at exploring the attitudes of clinicians (psychiatrists) with regard to the treatment of SPMI patients with a very low chance of recovery, poor quality of life, and acute or latent risk of dying. The papers are arranged in two thematically differently oriented sections.

Paper section I is concerned with the acceptability and suitability of PC approaches in the context of SPMI. The section contains three papers. The first paper reports on results from the survey on attitudes of psychiatrists practicing in Switzerland on the topic. Participating physicians were asked to respond to statements surrounding *goals of care* for SPMI patients, as well as questions regarding the *conceptualization* of SPMI, particularly in relation to fatality and futility. The goal of the survey was to get a sense of how palliative care and other controversial concepts such as *death* and *futility* are accepted by the respondents and to what degree they view them as suitable in order to improve care for SPMI patients. In the light of the absence of any clinical framework on how to value treatment goals for this group of patients or treatment guidelines, this seemed an important stepping stone before further pondering on the topic in papers two and three. Paper two is a book chapter summarizing the debate surrounding PC approaches and their suitability in the treatment of SPMI. Paper three is a theoretical contribution addressing ethical implications of palliative sedation in the context of SPMI.

Paper section II is concerned with the practice of (M)AID in the context of SPMI. It was decided to clearly distinguish between PC approaches and (M)AID. The first paper reports on the results of the above-mentioned survey regarding acceptability and support for the practice of (M)AID at both a general level and for the case vignettes presented in the introduction specifically. The second paper of this section is a letter to the editor published as a response to a report on a study on Dutch data with regard to (M)AID and euthanasia.

| Section I: Suitability of Palliative Care Approaches

Acceptability of Palliative Care Approaches for Patients with Severe and Persistent Mental Illness: A Survey of Psychiatrists in Switzerland

Article accepted for publication in BMC Psychiatry

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Abstract

Background. Some patients develop severe and persistent mental illness (SPMI) which is therapy-refractory. The needs of these patients sometimes remain unmet by therapeutic interventions and they are at high risk of receiving care that is inconsistent with their life goals. Scholarly discourse has recently begun to address the suitability of palliative care approaches targeting at enhancing quality of life for these patients, but remains to be developed.

Method. A cross-sectional survey asked 1311 German-speaking psychiatrists in Switzerland (the total number of German-speaking members of the Swiss Society for Psychiatry and Psychotherapy) about the care of SPMI patients in general, and about palliative care approaches in particular. 457 (34.9%) returned the completed survey. In addition, participants were asked to evaluate three case vignettes of patients with SPMI.

Results. The reduction of suffering and maintaining daily life functioning of the patient were rated as considerably more important in the treatment of SPMI than impeding suicide and curing the underlying illness. There was broad agreement that SPMI can be terminal (93.7%), and that curative approaches may sometimes be futile (e.g. 72.4% for the anorexia nervosa case vignette). Furthermore, more than 75% of the participating psychiatrists were in favour of palliative care approaches for SPMI.

Conclusions. The results of the present study suggest that the participating psychiatrists in Switzerland regard certain forms of SPMI as posing high risk of death. Additionally, a majority of respondents consider palliative care approaches appropriate for this vulnerable group of patients. However, the generalizability of the results to all psychiatrists in Switzerland or other mental health professionals involved in the care of

SPMI is limited. This limitation is important considering the reservations towards palliative care in the context of psychiatric illness, mainly because of the association with death and futility. Palliative care approaches, however, are applicable in conjunction with other therapies intended to prolong life. A next step could be to involve service users and develop a consensus of what palliative care might encompass in SPMI. A framework for identifying which patients might benefit from palliative care, should be explored for the future development of care for SPMI patients.

Introduction

> According to the World Health Organization:
>
> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2014).

Based on this broad definition, some psychiatric interventions may be considered palliative, as they aim primarily to enhance quality of life by means of adequate symptom control and by focusing on disability rather than on curing the illness (Trachsel et al., 2016b). However, palliative care as a deliberate approach has not been widely implemented in mental healthcare, and its tools have not been deployed in psychiatric practice. Its relevance in the treatment of certain severe and persistent mental illness (SPMI) such as severe and persistent depression, schizophrenia and anorexia nervosa has only recently been suggested (Berk et al., 2012, 2008; Lopez, Yager, & Feinstein, 2009; Trachsel et al., 2016b; Trachsel, Wild, Biller-Andorno, & Krones, 2015). Studies have consistently shown higher mortality among patients with SPMI (Reininghaus et al., 2015; Walker, McGee, & Druss, 2015), who die 10 to 20 years earlier on average than persons in the general population (Colton & Manderscheid, 2006; Olfson, Gerhard, Huang, Crystal, & Stroup, 2015). At the same time, a large body of research has focused on ultra-high risk and prodromal paradigms, representing a clear emphasis on early interventions at the cost of the development of adequate psychosocial care for patients in later stages of the disease (Appelbaum, 2017; Van Os & Guloksuz, 2017). Although full remission or recovery is the primary goal of acute psychiatric treatment, a substantial number of patients diagnosed with a major depressive disorder are resistant to evidence-based treatments, including treatments for chronic depression such as electro-convulsive therapy (Lima et al., 2013) or ketamine infusion (Andrade, 2017), and remission rates decrease with each additional treatment trial (Rush et al., 2006). In cases of schizophrenia, about one fifth of all patients show little or no therapeutic response and exhibit increased susceptibility to several life-threatening comorbidities (Kennedy, Altar, Taylor, Degtiar, & Hornberger, 2014). For these patients, evidence-based illness-modifying approaches are unavailable or remain ineffective, leading to low quality of life and frequent use of healthcare services (Berk et al., 2008). The contentious scholarly discourse surrounding

the application of palliative care approaches centres on the futility debate and is often linked to anecdotal reports, usually in the context of severe anorexia nervosa (Berk et al., 2008; Bruni & Weijer, 2015; Geppert, 2015; Lopez et al., 2009; McKinney, 2015; Trachsel et al., 2015; Trauer, 2012; Yager, 2015). In these circumstances, there is a risk that palliative care approaches in psychiatry may be perceived as inevitably intertwined with 'giving up' and losing hope rather than as complementary to recovery-oriented models (Anthony, 1993) for specific cases of SPMI. However, it is important to acknowledge that additional experimental treatment trials (e.g. low yield, higher risk polypharmacy) can sometimes leave patients more demoralized as they are caught in a cycle of false hope (Berk et al., 2008). For patients with a low probability of a favourable treatment outcome, it is therefore important to develop a modern concept of supportive care that does not ignore or trivialise the catastrophic effect some mental illnesses can have. Such approaches should focus on a psychosocial support system that goes beyond the traditional mindset of psychiatric care. The acceptability of certain palliative care approaches for severe and persistent mentally ill patients whose needs cannot be met by contemporary therapeutic interventions, however, is unclear. Since psychiatrists are the main decision makers when it comes to SPMI patients, it is crucial to initially explore the extent of acceptance of palliative care approaches in treating SPMI patients. We therefore asked practicing physicians with a specialist training in psychiatry (hereinafter: psychiatrists) to evaluate the suitability of such approaches. The main research questions concerned whether psychiatrists in Switzerland considered palliative care approaches to be appropriate for SPMI in general and for certain diagnostic groups in particular, and how they evaluated futility in specific cases. Additionally, we were interested in the prioritization of common treatment goals in cases of SPMI, such as everyday functioning and the reduction of suffering.

Methods

A quantitative cross-sectional survey was conducted in cooperation with the Swiss Society for Psychiatry and Psychotherapy (SSPP), in accordance with the ethical review processes of the University of Zurich and the checklist for the ethical evaluation of empirical studies.

Sample

The sample comprised all German-speaking members of the SSPP who are practicing psychiatrists (n = 1311), corresponding to approximately 30 percent of

psychiatrists in Switzerland. About 70 percent of psychiatrists in Switzerland are either French- or Italian-speaking or are not SSPP members. The rationale for sampling solely from members of the SSPP lies in the fact that in Switzerland, reliable contact information of physicians is only available in cooperation with relevant professional organizations such as the SSPP in which membership is not mandatory for psychiatrists. The SSPP contacted all participants prior to the survey to inform them of its purpose. Data were collected in the period February–March 2017.

Procedure

All participants received a hard copy of the survey with an enclosed prepaid return envelope (paper-pencil format). There was no incentive for participation. Participants also received a reminder postcard four weeks later.

Survey and Case Vignettes

The cross-sectional survey was based on the research questions. The case vignettes drew on previously published material (Baweja & Singareddy, 2013; Brenner et al., 1990; Trachsel et al., 2015) and were adapted to suit the format and goal of the survey (see Table 3). The content of survey items and case vignettes was revised by an advisory group that included experts and trainees in psychiatric practice and/or research, as well as biostatisticians. Participants were asked to respond to 18 items on a 7-point Likert scale, ranging from *completely disagree* (-3) to completely agree (+3), with a neutral mid-point (0), or from *unimportant* (score: 0) to *very important* (6). (See Table 4 for all survey items.) Items related to the three case vignettes (7 questions in each) adopted the same response format. The total number of items (including case vignettes) was 42. The WHO definition of palliative care (World Health Organization (WHO) 2014., 2014) was also provided.

Table 3

Case Vignettes Based on Modified Versions of Previously Published Cases (6,22,23)

Case 1: 37-year-old female with anorexia nervosa, onset at age 11
Symptoms: general muscle weakness; loss of bone density; amenorrhea; current weight 24kg/52 lbs; BMI 9.5 kg/m2; no recent weight gain or stabilization; no acute danger of dying, as her body is adapted to being underweight.
The patient underwent 10 previous inpatient treatments (in both somatic and psychiatric hospitals), three of which were in specialized psychiatric institutions. Throughout the

course of disease, different intensive psychotherapies have been tried, without success. During hospitalizations, the patient underwent several artificial re-feedings, sometimes under sedation. The patient now refuses artificial re-feeding and treatment. She states that, for years, her life has been focused exclusively on trying to overcome her anorexia, leaving her without friends or hobbies. She suffers from the physical symptoms, including general muscle weakness and loss in bone density, saying that she would rather die than undergo further treatment and wishes to be left in peace. She does not want to be forced into eating anymore. Two experts have declared that the patient has decision-making capacity to refuse further treatment, with consequent risk of dying.

Case 2: 33-year-old male with schizophrenia, onset at age 17, no significant comorbidities

Positive symptoms: auditory and visual hallucinations, persecutory delusions. Negative symptoms: apathy, social withdrawal, poverty of speech (all rated severe).

Despite long-lasting, high-dose pharmacological treatment (several atypical neuroleptics, haloperidol, clozapine and combinations of these), as well as electro-convulsive therapy, the patient has never been free from positive or negative symptoms. Multiple psychotherapies of various kinds have also failed to stabilize the patient or to improve his quality of life. He does not wish to continue assertive community treatment because he feels it is too intrusive. While the positive symptoms were more dominant in the first years following initial diagnosis, he went on to develop severe negative symptoms, as well as aggression and self-injurious behavior such as burning himself with cigarettes. The negative symptoms and his strong functional deficits are exacerbated by chronic unemployment and inability to live independently, and the patient has no family system. His persisting illness has left him completely isolated, with no social contacts and no hobbies or interests. Two experts have declared that he possesses decision-making capacity in respect of his illness and its treatment.

Case 3: 40-year-old male with major depressive disorder, no significant comorbidities

Symptoms: energy loss, insomnia, fatigue, persistent suicidal ideation over 20 years, current acute and concrete suicidal intent.

The patient underwent different intensive, evidence-based, long-term psychotherapies, including specialized treatment approaches such as CBASP and IPT. His depression was not improved either by psychotherapy alone or in combination with adequate treatment trials of antidepressants (selective serotonin reuptake inhibitors, tricyclic antidepressants, venlafaxine, augmentation with lithium and antipsychotic medications (quetiapine and aripiprazole). The patient experienced significant adverse effects with several of the medications. Exhausted and as a last resort, he has decided to undergo electro-convulsive therapy. However, maintenance electro- convulsive therapy proved equally ineffective in preventing the reappearance of suicidal ideation; indeed, the symptoms worsened. The patient experiences severe hopelessness and states that his quality of life is very poor, that he doesn't want to deal with his illness anymore, and that he plans to commit suicide in the near future. Two experts have declared that he possesses decision-making capacity regarding his illness and its treatment.

To examine how psychiatrists would evaluate a patient's life expectancy, the case vignettes included a 'surprise question' ('I would not be surprised if this patient died within the next 6 months'; see item S in Table 4). In palliative care, variants of the surprise question are often used for patient prognosis near the end of life (White, Kupeli, Vickerstaff, & Stone, 2017). The survey included items concerning attitudes to palliative sedation and physician-assisted dying for SPMI patients (see items O, P, Q, R, X and Y in Table 4). These are reported in a separate article.

Table 4

Survey Items

I: Questions on the treatment of patients with severe and persistent mental illness (SPMI)

In the treatment of patients with severe and persistent mental illness (SPMI), how important is:

A) curing the illness
B) reduction of suffering
C) the patient's ability to function in daily life
D) the patient remaining autonomous in their decision making
E) impeding suicide

According to the World Health Organization (WHO), palliative care 'is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.
How strongly do you agree or disagree with the following.

F) For me, the term 'palliative' relates directly to end of life.
G) For some SPMI patients, palliative care is indicated.
H) In psychiatry, applying a palliative care model is important in providing optimal support for certain patients without a life-limiting medical illness.
I) In severe, chronic and therapy-refractory anorexia nervosa, a palliative approach would be suitable.
J) In severe, chronic and therapy-refractory schizophrenia, a palliative approach would be suitable.
K) In severe, chronic and therapy-refractory depression, a palliative approach would be suitable.
L) In severe, chronic and therapy-refractory bipolar disorder, a palliative approach would be suitable.
M) In severe, chronic and therapy-refractory substance disorder, a palliative approach would be suitable.

How strongly do you agree or disagree with the following.

N) SPMI can be a terminal illness.
O) Sedation for the reduction of unbearable refractory psychological symptoms is justifiable in certain cases of SPMI.
P) I would generally be willing to perform sedation as mentioned above in 'O'.
Q) I generally advocate access to assisted suicide for patients with SPMI.
R) If physician-assisted suicide was legally permitted for SPMI, I would support my patients in seeking this intervention as the physician of record or by referring them to another physician.

II: Questions about the three case vignettes
Please evaluate the case vignettes as below.

S) I would not be surprised if this patient died within the next 6 months.
T) For this patient, further interventions to cure the anorexia would most likely be futile.
U) In this case, I would be comfortable with a reduction of life expectancy in order to increase or maintain quality of life if consistent with the patient's goals.
V) In this case, I would accept a temporary decrease in quality of life due to coercive measures.

W) In this case, I would not proceed against the patient's wishes.
X) In this case, sedation to reduce an unbearable refractory symptom is reasonable.
Y) If physician-assisted suicide was legally permitted, I would support this patient if this was her explicit and enduring wish, referring her to appropriate care.

Note. Questions S–Y applied to all three case vignettes in Table 3.

Statistical Analysis

Arithmetic means were calculated for age and work experience, and descriptive statistics (percentages) were calculated for gender, as well as for all Likert scale items. In order to facilitate readability of the results, Likert scale items were collapsed into three categories (1, 2, 3 = agree, 0=neutral, -1, -2, -3 =disagree) in the running text.
We included 100% of participants and used available-case analysis, i.e., we indicated the number of missing cases separately for every question, because the low number of missing cases.

Results

The survey was mailed to 1311 active members of the SSPP, and 457 surveys (34.9%) were returned of which 85% were fully completed. Of the respondents, 58.8% were male, and 4.2% did not indicate their gender. This gender distribution reflected the total sample of active SSPP members (62.9% male vs. 37.1% female). Mean age was 57.8 years (SD = .43; 95% confidence interval [CI] = 56.9, 58.6; range 35 - 88, missing *n* = 20), and mean work experience was 27.7 years (SD = .44; CI = 26.8, 28.6; missing *n* = 23).

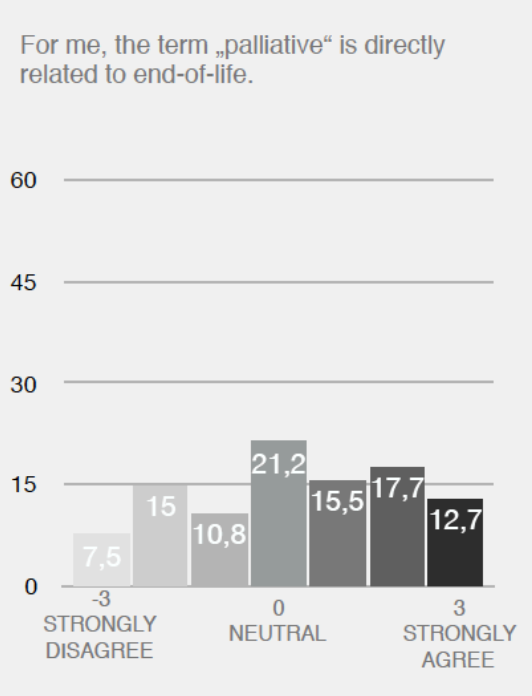
Views on the General Goals of Care in Severe and Persistent Mental Illness

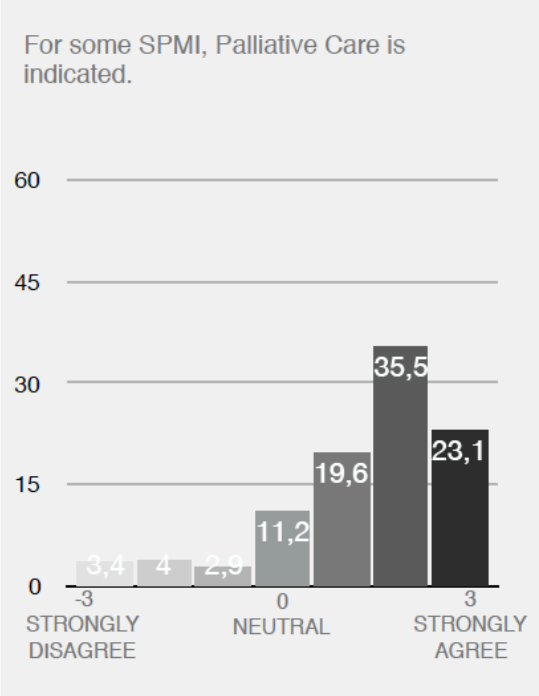
In relation to treatment goals for SPMI, respondents most frequently rated reduction of suffering as either important or very important (ratings of 5 or 6 in 94.1% of responses; CI = 91.5%, 95.9%; missing *n* = 1). This was followed by daily life functioning (ratings of 5 or 6 in 90.8% of responses; CI = 87.8%, 93.1%; missing *n* = 1), autonomy (ratings of 5 or 6 in 76.0% of responses; CI = 71.9%, 79.7%; missing *n* = 3), and impeding suicide (ratings of 5 or 6 in 66.1% of responses; CI = 61.6%, 70.3%; missing *n* = 3). Only 11.0% of respondents rated curing the illness as an important goal (ratings of 5 or 6; CI = 8.4%, 14.2%); a further 49.4% considered this moderately important (ratings of 3 or 4; CI = 44.8%, 54.1%; missing *n* = 10).

Views on Palliative Care and Its Use in Patients with Severe and Persistent Mental Illness

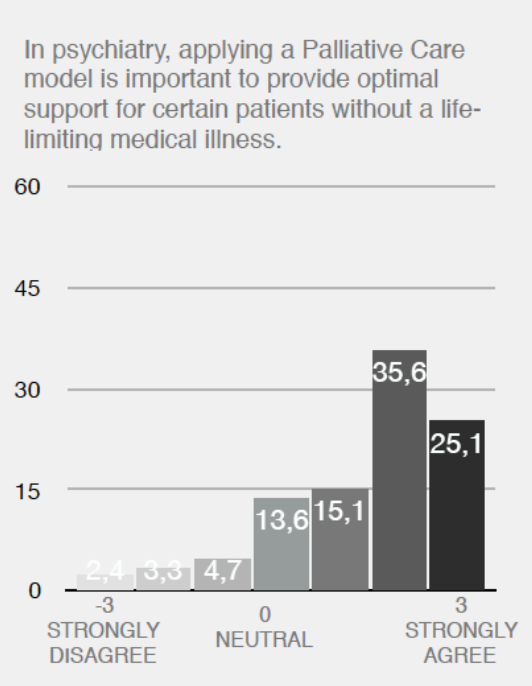
For 45.4% of respondents, the term 'palliative' related directly to end of life (ratings of 1, 2 or 3; CI = 40.8%, 50.0%); 21.2% remained neutral (rating 0; CI = 17.7%, 25.2%), and 33.4% did not relate the term to end of life (ratings of -1, -2 or -3; CI = 29.2%, 37.9%; missing *n* = 5). While 78.2% (CI = 74.1%, 81.8%) of respondents said that palliative care approaches were indicated for certain SPMI, 11.2% (CI = 86.3%, 14.5%) remained neutral (missing *n* = 12). Similarly, 75.8% (CI = 71.6%, 79.5%) of respondents thought that application of a palliative care model was important in providing optimal support for certain patients without a life-limiting illness, and 13.6% (CI = 10.7%, 17.0%) remained neutral (missing *n* = 7). However, 94.5% (CI = 92.0%, 96.2%) of all respondents believed that SPMI could be terminal while 4.4% (CI = 2.9%, 6.7%) remained neutral (missing *n* = 4).

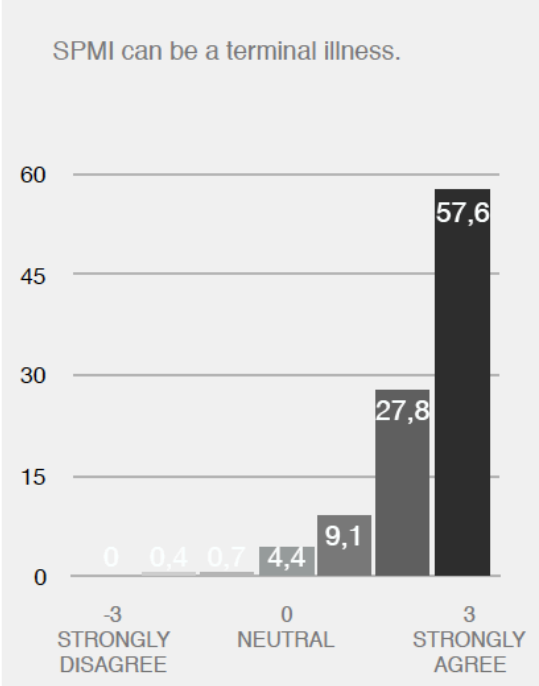
When asked about the application of palliative care approaches to different mental disorders, respondents found this most suitable for severe, chronic and therapy-refractory schizophrenia (76.28 rating 1, 2 or 3; CI = 72.8%, 80.5%; missing *n* = 4) and for substance disorders (75.3% rating 1, 2 or 3; CI = 71.1%, 79.0%; missing *n* = 4). Palliative care approaches were found almost equally suitable for chronic and therapy refractory depression (70.4.7% rating 1, 2 or 3; CI = 66.1%, 74.4%; missing *n* = 4); bipolar disorder (67.8% rating 1, 2 or 3; CI = 63.3%, 72.0%; missing *n* = 4); and anorexia nervosa (67.7% rating 1, 2 or 3; CI = 63.3%, 71.9%; missing *n* = 5).

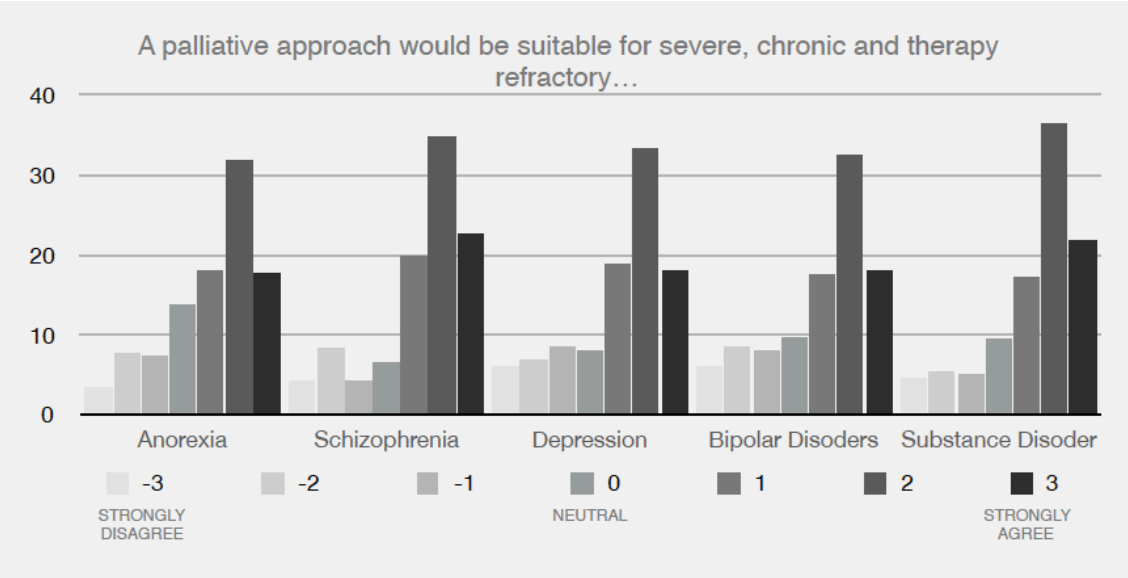




Note. Psychiatrists' attitudes to palliative care and severe and persistent mental illness.







Note. Psychiatrists' attitudes to palliative care and severe and persistent mental illness.

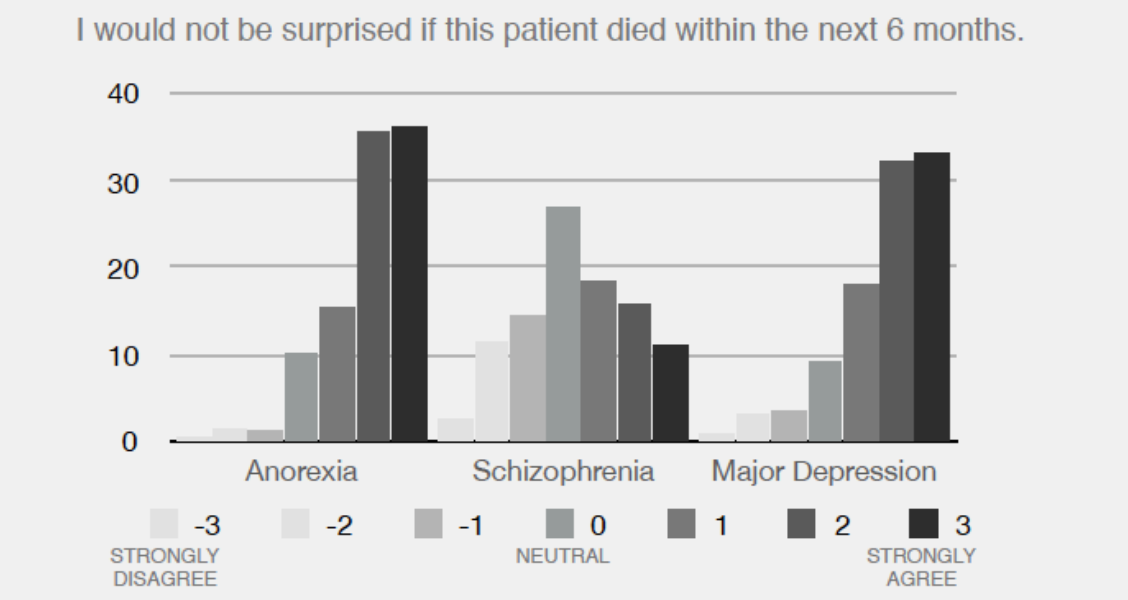
Responses to Vignettes

Anorexia nervosa. A majority of respondents indicated that they would not be surprised if the anorexia nervosa patient died within the next 6 months (87.2% rating 1, 2 or 3, where 3 designated *strongly agree*; CI = 83.8%, 90.0%; missing n = 3). (For all case vignettes, see Table 1). Most respondents agreed that further interventions to cure the anorexia nervosa would most likely be futile (73.1% rating 1, 2 or 3; CI = 68.8%, 77.0%; missing *n* = 4), and 82.3% (CI = 78.5%, 85.5%) indicated that they would be comfortable with a reduction in life expectancy in order to increase or maintain quality of life in such cases (missing *n* = 5).

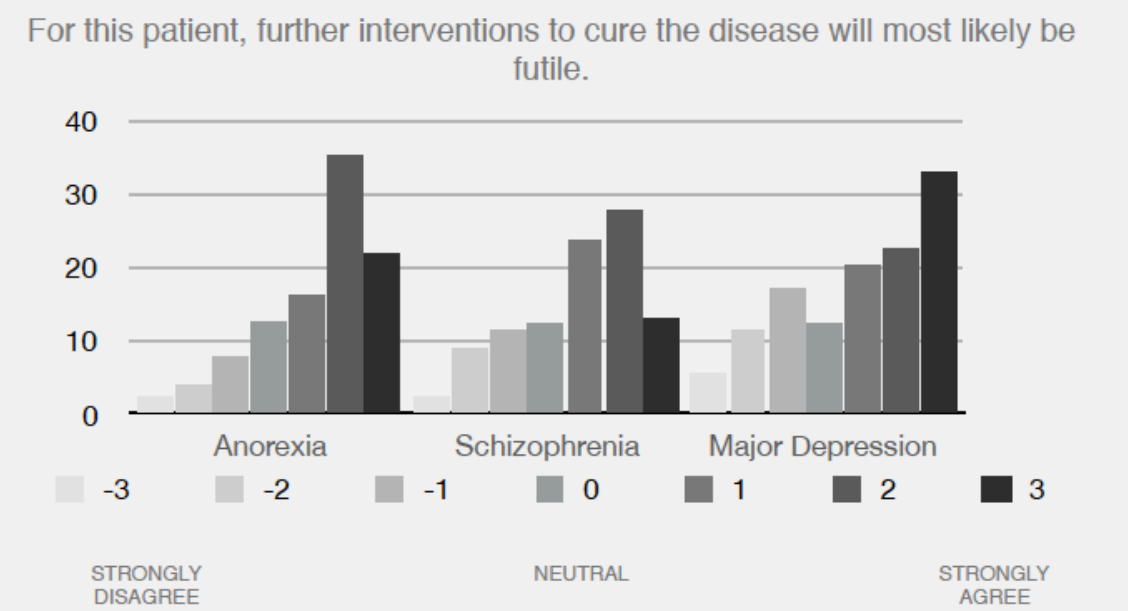
Schizophrenia. While almost half of respondents indicated that they would not be surprised if the patient diagnosed with schizophrenia died within the next 6 months (45.1%; CI = 40.9%, 49.3%), more than a quarter remained neutral (26.9% rating 0; CI = 23.0%, 31.2%) with regard to this item (missing *n* = 7). A majority agreed that further interventions to cure the schizophrenia would most likely be futile (64.8% rating either 1, 2 or 3; CI = 60.2%, 69.0%; missing *n* = 9), and 72.8% (CI = 68.5%, 76.7%) indicated that they would be comfortable with a reduction of life expectancy in order to increase or maintain quality of life (missing *n* = 9).

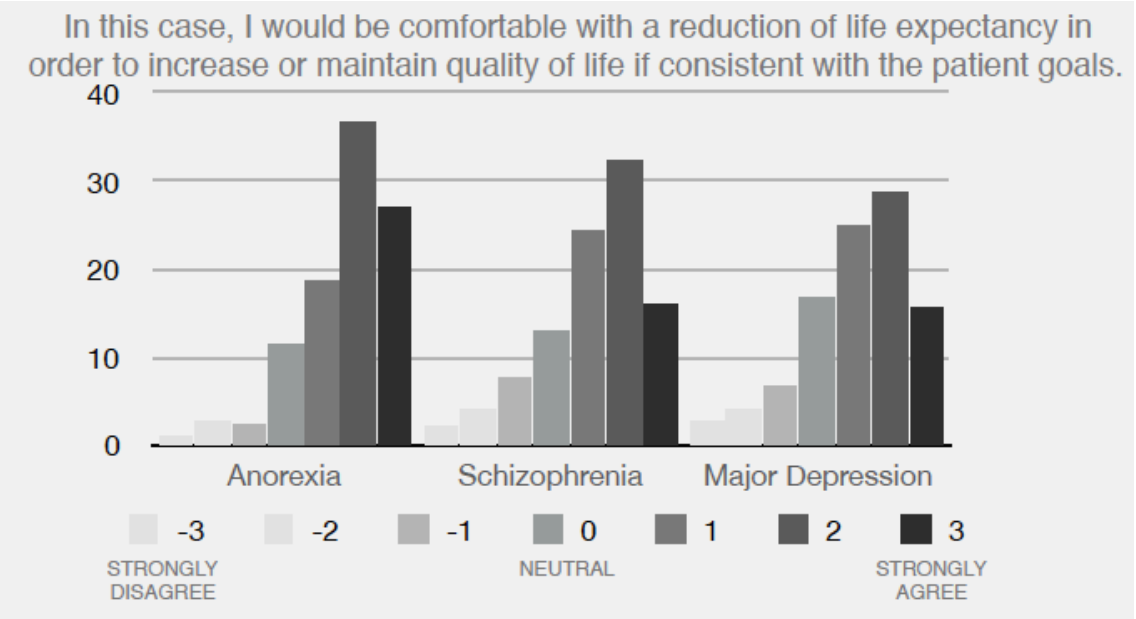
Major depressive disorder. A sizeable majority of respondents indicated that they would not be surprised if the patient diagnosed with major depressive disorder died within the next 6 months (83.8% rating 1, 2 or 3, where 3 designated *strongly agree*; CI

= 80.1%, 86.9%; missing *n* = 7). Slightly more than half agreed that further interventions to cure the depression would most likely be futile (53.6% rating 1, 2 or 3; CI = 48.9%, 58.1%; missing *n* = 7), and 69.3% (CI = 64.9%, 73.4%) indicated that they would be comfortable with a reduction of life expectancy in order to increase or maintain quality of life (missing *n* = 7).



Note. Summary of psychiatrists' attitudes to life expectancy, futility and quality of life with regard to the three clinical case vignettes.





Note. Summary of psychiatrists' attitudes to life expectancy, futility and quality of life with regard to the three clinical case vignettes.

Discussion

Acceptability of palliative care approaches in mental health care. In this survey of psychiatrists in Switzerland, almost all respondents believed that SPMI can be a terminal illness, and that *curing* the illness has a lower priority than other care goals such as *reduction of suffering* and *functioning in daily life*. These findings align with previous conceptual work which suggested that some existing clinical approaches in contemporary psychiatry can be considered palliative because their primary aim is not remission or illness modification (Trachsel et al., 2016b). The broad consensus about the fatality of certain severe cases of mental illness is particularly noteworthy given the 'loud silence' with regard to death and dying (other than suicide and its prevention) in mental healthcare. Premature mortality is a neglected aspect in mental health care. Accepting it as an unchangeable outcome (Ivbijaro, 2017), or completely ignoring it in the development of new treatment approaches is harmful to the most vulnerable of all patients. It is hoped that by acknowledging that this group of patients is at greater risk of dying (Liu et al., 2017), additional resources can be freed up in order to improve the care of these patients. In summary, our findings suggest widespread agreement among the respondents on the suitability of general palliative care approaches in treating SPMI. One issue raised by several participants in the comment section of the survey was the concern expressed by some experts about the possible impact of characterising mental health

treatments as ‘palliative’, which might be seen to imply ‘giving up’ on patients (Bruni & Weijer, 2015; Geppert, 2015; McKinney, 2015; Trauer, 2012, 2012). Indeed, the term ‘palliative’ may not be ideal, given its associations with terminal illness (Berk et al., 2008); almost half of our respondents felt that it was closely related to end-of-life care, indicating a heterogeneous understanding of palliative care, even among health care professionals.

It is important to stress that the use of palliative care in psychiatry (as in other areas of healthcare) need not exclude other treatment approaches. The features of palliative care approaches, such as the ongoing alliance with patients and their relatives (Berk et al., 2012), exquisite symptom management and pursuit of patient and family goals for care and for life in general are, for example, compatible and consistent with the principles of the recovery model (Berk et al., 2012). In this sense, palliative care approaches may offer psychiatrists additional tools in the care of SPMI, particularly where patient needs and goals cannot be met by current psychiatric interventions. However, the discomfort about introducing approaches that used to be reserved for a terminally ill population in psychiatric treatment of SPMI patients has to be taken seriously and has to be critically accompanied scientifically. Specifically, it has to be evaluated whether using a less loaded term such as *supportive care* can improve acceptance of the concept.

With regard to the case vignettes, participants prioritized quality of life over patients’ remaining life expectancy, and in all three cases, the great majority doubted that further interventions to cure the illness would be successful. This finding aligns with conceptual questions concerning the importance of *curing* SPMI as compared to other goals of care such as *reduction of suffering* and *functioning in daily life*. The overall consensus that curative approaches would most likely be futile in certain specific cases of SPMI confirms the need to further explore the concept of medical futility in psychiatry. Objections to the applicability of this concept in cases of chronic psychiatric illness are multifaceted (Geppert, 2015; Yager, 2015). However, even if one accepts these arguments and concludes that the concept is not relevant in the context of mental illness, the question remains of how best to deal with the reality of unremitting or progressively declining mental illness. In summary, while it could be argued that the recovery-based model and the harm reduction approaches already seek to minimize symptoms in acute and maintenance phases, we believe that the considerations above have implications that

go beyond of what is currently available, especially with regard to futility and last resort therapeutic interventions.

Lack of specificity of the conceptual framework. It seems clear that the concepts and framework underpinning palliative care approaches in a psychiatric context require further elucidation, including the issue of how specific palliative care interventions might be implemented. In particular, advocates need to elaborate how palliative care might be applied to psychiatric illness, including the prevention and relief of suffering, prevention of futile and burdensome interventions (Trauer, 2012) and improvement of quality of life. Any such investigation of the feasibility of specific palliative care interventions lies beyond the scope of the present study. It should also be noted that the WHO definition of palliative care provided in the survey (see Table 4) was described by several respondents as vague and applicable to many (if not all) forms of psychiatric treatment. The high variability in the results might be one indication for a lack of consensus on what palliative care approaches in this context would comprise. This aspect hast to be taken into consideration when interpreting the data, and it will be crucial to develop a minimum consensus regarding the definition of palliative care approaches in order to further develop this area.

Strengths and Limitations

The present study has a number of strengths. Previously, palliative care approaches in psychiatry have been discussed mainly at a conceptual level by ethicists and experienced clinicians. We are aware of only one other study that tackles the topic empirically through qualitative interviews (McGrath, Koilparampil, Koshy, & George, 2009), focusing on commonalities between contemporary mental healthcare and palliative care philosophies. It is argued here that the similarities between mental health services and palliative care principles can serve as a foundation for integrating these approaches into mental health services.

The present study is the first survey to use quantitative methods to explore mental health professionals' attitudes to the treatment of SPMI patients in general, and to the use of certain palliative care approaches in particular. In light of the controversy surrounding that discussion, this insight is an important first step towards establishing the relevance of the palliative care concept in mental health care.

The study also has several limitations. Although Likert scale items are an accepted means of conducting quantitative surveys, the options offered can only approximate

complex multidimensional concepts. In assembling the study's advisory group, our rationale was to include on the one hand persons who were able to advise us with relevant knowledge on the research questions and the content of the survey including experts and trainees in psychiatry, psychology, and palliative care, and on the other hand, professionals with regard to survey design issues and statistics (psychologist and biostatistician). However, it's a limitation that no other stakeholders such as patients, family, or policy makers have been part of the advisory board. The present evidence depends on only 457 completed surveys. This corresponds to about 10 percent of psychiatrists in Switzerland. In addition, the sample was confined to German-speaking members of the SSPP and may not be representative for all psychiatrists practicing in Switzerland. Furthermore, the results are not generalizable to other mental health care professionals who might be involved in the care of patients with SPMI such as nurses and psychologists. The nonresponse rate raises the possibility of response bias. It might be possible that psychiatrists with particular pre-existing normative beliefs were disproportionally represented. However, the demographics correspond to the total of all psychiatrists in Switzerland and the results have a high variability, suggesting a minor impact of the response bias on our data. Lastly, it is important to note that an available case analysis was used in order to minimize loss of data.

Lastly, it is important to note that an available case analysis was used in order to minimize loss of data but that the known disadvantages of this, e.g., that the standard of errors computed by most software packages uses the average sample size across analyses, do not apply for our study because we haven't used inferential statistics and used available cases for SD's and confidence intervals as well.

Implications for Clinical Practice

The present findings indicate that many psychiatrists—at least in Switzerland—consider that palliative care approaches may be suitable for certain cases of SPMI. For clinical practice, this means that palliative care represents a possible option in the treatment of SPMI patients and the psychiatric profession's readiness to introduce some of these tools to clinical care. To explore this option, the psychiatric profession must design a framework for use and a common language for the field, and must subsequently create an evidence base capturing the impact on clinical outcomes for SPMI patients. Most importantly, palliative approaches must be seen as an addition to rather than a replacement for other novel and promising person-centred approaches, such as the

recovery movement (Anthony, 1993; Berk et al., 2012). It remains open whether the term 'palliative' will have majority appeal or whether palliative care principles will merely inform a modern concept of psychosocial support for SPMI patients.

Future Research

While this study offers some insight into how the surveyed psychiatrists appraise the implementation of palliative care approaches in mental healthcare, it is mainly to be interpreted as a starting point of the discussion. It remains unclear how the concept might be assessed by affected patients, and the specifics of palliative care interventions remain to be defined. The next step will be to develop a framework for differential indication—that is, to identify which patients would qualify for or benefit from a palliative care approach. It will be crucial for further development to adequately involve patients and put their needs first.

Declarations

Ethics approval and consent to participate. This study was outside the scope of the Swiss Human Research Act (HRA) (Swiss Federal Council, 2014) because no personal data concerning human diseases and concerning the structure and function of the human body were collected. However, the study has been assessed according to the 'Checklist for the Ethical Evaluation of Empirical Studies that Don't Need Mandatory Authorization' (CEBES); No. CEBES-2016-04. Identities of subjects were completely anonymous ('blind survey') and the study was of non-interventional nature. Collecting consent documentation in this case would hamper anonymity, which is why the need for informed consent was waived for this study. However, a cover letter provided information regarding purpose and aim of the study, handling of data, as well as funding bodies and contact information of the principal investigators. Completion of the survey posed minimal risks to the subjects.

Consent for publication. Not applicable.

Availability of data and material. The datasets used and/or analysed during the current study are available from the corresponding author on reasonable request.

Competing interests. None.

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Authors' contribution. MT and MAH constructed and conducted the survey, analysed the data and drafted the manuscript. All authors were involved in the study's conception and design, interpretation of the data, critical revision of the article and final approval of the version submitted for publication.

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Palliative Care in der Behandlung von schweren chronischen psychischen Störungen

Book chapter in "Ethik in der psychiatrischen Praxis – Prinzipien – Werte – Tugenden", Christian Prüter-Schwarte, Euphrosyne Gouzoulis-Mayfrank, Pabst: Köln.

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Palliative Care - Reorientierung der Behandlungsziele mit Fokus auf die Lebensqualität

Das Lindern von Leiden und der zentrale Fokus auf die Lebensqualität schwer kranker Menschen bilden zentrale Pfeiler der Palliative Care. Palliative Care hat ihren Ursprung zwar in der modernen Hospizbewegung (Saunders, 2001), umfasst aber heute wesentlich mehr als reine Sterbebegleitung. Laut der World Health Organization (WHO) entspricht "Palliative Care einer Haltung und Behandlung, welche die Lebensqualität von Patienten und ihren Angehörigen verbessern soll, wenn eine lebensbedrohliche Krankheit vorliegt. Sie erreicht dies, indem Schmerzen und andere physische, psychosoziale und spirituelle Probleme frühzeitig und aktiv identifiziert, immer wieder erfasst und angemessen behandelt werden" (World Health Organization (WHO) 2014., 2014). Palliative Care umfasst also sowohl medizinische als auch pflegerische und psychologische Interventionen sowie die Koordination und Kommunikation zwischen den verschiedenen involvierten Akteuren in der Fürsorge für Patientinnen mit lebensbedrohlichen Krankheiten (Morrison & Meier, 2004). Mit der oben zitierten neuesten Definition weitet die WHO das Konzept der Palliative Care im Vergleich zu früheren Definitionen auch auf Erkrankungen aus, die (noch) nicht im terminalen Stadium sind. Zeitgenössische Palliative Care versteht sich als heilungsorientierten Ansätzen nicht direkt gegenübergestellt, sondern wird auch parallel zu kurativen Interventionen angewandt. Dabei hat sie primär zum Ziel, Symptome zu lindern und die Lebensqualität der Patientinnen zu erhalten oder zu verbessern. Die zahlreichen positiven Effekte von Palliative Care für lebensbedrohlich erkrankte Patientinnen und deren Angehörige führten in den letzten Jahren zu einer stetigen Ausweitung ihres Anwendungsfeldes (Hughes & Smith, 2014). Der Bedarf nach Palliative Care wird auch in Zukunft, im Rahmen des demographischen Wandels und dem häufigeren Auftreten von chronischen

Krankheiten, zunehmen (Sachs, Shega, & Cox-Hayley, 2004). Längst wird Palliative Care nicht mehr nur im Rahmen onkologischer Erkrankungen angewandt, sondern auch in der Pflege und Fürsorge von Personen mit Demenz und anderen chronisch und lebensbedrohlich erkrankten Patientinnen als zentral angesehen (Baker, 2005). Auch psychiatrische Fachpersonen sind in der modernen Palliative Care zahlreich vertreten und leisten dort einen wichtigen Beitrag, um den komplexen und vielseitigen Bedürfnissen lebensbedrohlich kranker Patientinnen gerecht zu werde (Chochinov & Breitbart, 2009), z. B. in der Psychoonkologie. Obwohl von verschiedenen Seiten argumentiert wird, dass Palliative Care und die Psychiatrie eine ähnliche Grundhaltung teilen (Berk et al., 2012), gibt es in der Psychiatrie bis dato keine explizit als palliativ bezeichneten Ansätze. Der Diskurs, ob und wie Palliative Care auch bei schweren und chronischen psychischen Störungen positive Effekte auf Symptome und Lebensqualität haben könnte und ob einige psychiatrische Interventionen de facto palliativer Natur sind (Trachsel et al., 2016b), wird erst seit Kurzem geführt.

Das Konzept der Medical Futility und dessen Rolle bei psychischen Störungen

Die Relevanz von Palliative Care im psychiatrischen Kontext wurde erstmals im Zusammenhang mit der Debatte um die sogenannte Medical Futility (nachfolgend Futility) genannt (Lopez et al., 2009). Futility ist ein in der somatischen Medizin etabliertes Konzept und lässt sich sinngemäß mit medizinischer Aussichtslosigkeit übersetzen. Konkret wird der Begriff Futility dann verwendet, wenn eine bestimmte medizinische Intervention bei Patientinnen als potentiell ineffektiv angesehen wird, eine Verbesserung der medizinischen Situation herbeizuführen. In der Psychiatrie wurde Futility bisher primär im Zusammenhang mit an schwersten Anorexien erkrankten Patientinnen diskutiert, die sich aufgrund ihrer psychischen Störung in einer lebensbedrohlichen Situation befinden (Bruni & Weijer, 2015; Geppert, 2015; Lopez et al., 2009; McKinney, 2015; Trachsel et al., 2015; Yager, 2015). Lopez, Yager und Feinstein (2009) haben anhand einer klinischen Fallvignette Kriterien beschrieben, unter denen das Futility-Konzept und im weiteren Verlauf Palliative Care bei psychischen Störungen eine Rolle spielen könnte.

Bei der beschriebenen 30-jährigen Patientin wurde im Alter von 19 Jahren eine Anorexia nervosa diagnostiziert. Zahlreiche Behandlungsversuche – unter anderem eine stationäre Behandlung über zwei Jahre und mehrere Jahre in einer ambulanten

Tagesklinik – scheiterten mit dem Ziel, den Zustand der Patientin zu verbessern oder zumindest zu stabilisieren. Zum beschriebenen Zeitpunkt hatte die Patientin einen Body Maß Index von 10.9 und wurde aufgrund eines lebensbedrohlichen Sturzes gegen ihren Willen hospitalisiert. Das staatliche Krankenhaus, in welchem sie hospitalisiert war, sowie eine spezialisierte Therapieeinrichtung für Langzeitpatientinnen mit Essstörungen weigerten sich jedoch, die Patientin nach Stabilisierung gegen ihren Willen aufzunehmen. Aufgrund der prekären, lebensbedrohlichen Situation in der sich die Patientin befand, wurden sämtliche Experten konsultiert, die sich über die letzten zehn Jahre intensiv mit der Patientin beschäftigt hatten. Die Anorexia nervosa der Patientin wurde unter den gegenwärtig zur Verfügung stehenden Behandlungsoptionen einstimmig als therapieresistent beurteilt. Die Patientin erfüllte zudem laut Rechtsexperten des Krankenhauses die zentralen Kriterien der Selbstbestimmungsfähigkeit[2] und hatte somit grundsätzlich das Recht, eine weiterführende Behandlung abzulehnen. Vom behandelnden Team wurde anschließend entschieden, dass eine weiterführende kurative Therapie inklusive notwendiger unfreiwilliger Klinikeinweisung und Zwangsbehandlung mit höchster Wahrscheinlichkeit zu keiner Verbesserung des klinischen Zustandes der Patientin führen würde und somit aussichtslos (futile) wäre. Die Autoren sahen den Wechsel zu einer palliativ orientierten, primär symptomlindernden Behandlung in diesem Fall als einzige ethisch vertretbare und würdevolle Alternative zu einem intrusiven, paternalistischen Vorgehen. Eine solche Anwendung des Futility-Konzeptes bei Patienten mit schweren chronischen psychischen Störungen ist jedoch nicht unumstritten (Bruni & Weijer, 2015; Geppert, 2015; McKinney, 2015). Die Vorbehalte sind vielschichtig: Einerseits wird argumentiert, dass gerade im Falle von Patientinnen mit Anorexie nervosa nicht von einer Therapieresistenz im eigentlichen Sinne die Rede sein kann, sondern dass es sich in solchen Fällen um eine Ablehnung einer Intervention handelt, die für die Patientin lebensrettend wäre (Geppert, 2015). Diese Situation ist ethisch besonders anspruchsvoll, wenn zusätzlich noch Zweifel an der Selbstbestimmungsfähigkeit der Patientin bestehen, welche die lebensrettende Therapie ablehnt. So ist es gerade bei Patientinnen mit schweren Essstörungen, jedoch auch bei anderen psychischen Störungen, schwierig zu beurteilen, inwiefern eine Ablehnung der Therapie auf fehlender

[2] Die entsprechenden Rechtsbegriffe lauten Einwilligungsfähigkeit in Deutschland respektive Urteilsfähigkeit in der Schweiz.

Krankheitseinsicht oder anderen krankheitsbedingten Symptomen basiert; bei Essstörungen basiert die Therapieablehnung z. B. auch oft auf einer irrationalen Angst vor dem Zunehmen und der dahinter liegenden Körperschemastörung. Es bleibt aber auch hier zu beachten, dass Behandlungsentscheidungen grundsätzlich keineswegs vernünftig sein müssen, sondern lediglich den Willen der Patientin abbilden sollen. Im geschilderten Fallbeispiel war es der Patientin laut den Autoren nicht möglich, die Konsequenzen der Ablehnung einer lebenserhaltenden Therapie zu antizipieren. Sie glaubte bis zum Schluss nicht daran, dass sie bei einem Therapieverzicht (in diesem Fall einer Einweisung und Ernährung mit Magensonde) sterben würde (Geppert, 2015; Lopez et al., 2009). Es bleibt unklar, wie in einem solchen Fall die Ziele der Patientin zu würdigen sind, da diese offensichtlich auf falschen Grundannahmen in Bezug auf ihre Erkrankung basieren. Vorbehalte bezüglich der Selbstbestimmungsfähigkeit schwerst psychisch erkrankter Personen sind denn auch das Hauptargument gegen eine Anwendung des Futility-Konzeptes und gegen die Initiierung von Palliative Care bei Patienten mit schweren chronischen psychischen Störungen, welche eine weitere kurative Behandlung ablehnen.

Palliative Psychiatrie – ein sinnvolles neues Konzept?

Der Diskurs rund um die Anwendung von Palliative Care in der Psychiatrie ist ähnlich kontrovers wie die Diskussion über das Futility-Konzept bei psychischen Störungen (Berk et al., 2012; Geppert, 2015; McGorry, 2005; Trauer, 2012). Es wurde argumentiert, dass Palliative Care in der Psychiatrie kein Anwendungsfeld habe, da der Begriff zu stark mit dem Lebensende verknüpft sei und dass den Patientinnen damit Hoffnungslosigkeit suggeriert werde (Trauer, 2012). Die Prinzipien der Palliative Care würden direkt mit anderen patientenzentrierten Ansätzen in der Psychiatrie wie beispielsweise der *Recovery* Bewegung konkurrieren (Trauer, 2012).

Andererseits wurde hervorgehoben, dass Palliative Care und Psychiatrie von ähnlichen Grundannahmen und -haltungen ausgehen und darum eine gute Basis dafür bestehe, Palliative Care in der Psychiatrie anzuwenden (McGrath et al., 2009). Tatsächlich pflegen sowohl die Palliative Care als auch die Psychiatrie eine patientenzentrierte und systemorientierte Praxis, betonen die Wichtigkeit der therapeutischen Beziehung und arbeiten in multidisziplinären Teams. Trachsel, Irwin, Biller-Andorno, Hoff und Riese (2016) haben die mögliche Bandbreite eines palliativen Ansatzes in der Psychiatrie (*Palliative Psychiatrie*) konzeptuell ausgearbeitet: Obschon viele psychiatrische Interventionen keine primär kurative Absicht haben, sehen die Autoren die Rolle von

Palliative Care vor allem bei schwerst psychisch erkrankten Patientinnen wie beispielsweise schwersten Schizophrenien und Anorexien. Ausgehend von Fällen wie dem oben beschriebenen, könnte ein Fokuswechsel von aggressiv-kurativ hin zu stützend-palliativ eine sowohl aus klinischer als auch aus ethischer Sicht wertvolle Option in der Behandlung von schwerst psychisch erkrankten Patientinnen sein (Berk et al., 2012; Lopez et al., 2009; McGorry, 2005; Trachsel et al., n.d., 2016b, 2015; Yager, 2015).Dabei ist es nicht von Relevanz, ob gewisse Patientinnen mit psychischen Störungen als terminal krank bezeichnet werden, da palliative Ansätze per definitionem unabhängig von der verbleibenden Lebenszeit angewendet werden können (World Health Organization (WHO) 2014., 2014). Laut Trachsel und Kollegen (2016) würde sich eine *Palliative Psychiatrie* dadurch auszeichnen, dass sie Unterstützung im Coping und der Akzeptanz von Symptomen bietet, beispielsweise in Form von Akzeptanz- und Commitment-Therapie (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). Zudem würden physiologische, psychologische, soziale und spirituelle Aspekte explizit in die Behandlung integriert und ein breites Supportsystem gewährleistet, das die Bedürfnisse der Patientinnen und ihrer Angehörigen so gut wie möglich aufnimmt und zufrieden stellt. Dabei hat ein palliativer Ansatz nicht primär eine Lebensverlängerung zum Ziel, sondern vielmehr die Lebensqualität der Patientinnen (Chochinov & Breitbart, 2009). Die Schweizerische Akademie der Medizinischen Wissenschaften sieht in einer Integration von palliativen Ansätzen in der Psychiatrie sogar das Potential, das Suizidrisiko bei der besonders vulnerablen Patientengruppe von chronisch psychisch erkrankten Patientinnen zu senken. Sie schreibt in ihren medizin-ethischen Richtlinien zu Palliative Care Folgendes:

> Viele psychiatrische Leiden können chronisch verlaufen oder sind durch häufige Rezidive charakterisiert. Umso wichtiger ist in solchen Fällen ein palliativer Ansatz, der nicht in erster Linie das Bekämpfen der Krankheit zum Ziel hat, sondern den bestmöglichen Umgang mit der Symptomatik oder Behinderung. Oft kann die Lebensqualität verbessert und das Suizidrisiko gesenkt werden, wenn zusätzlich zu kurativen bzw. störungsorientierten Behandlungen eine palliative Unterstützung und Zuwendung stattfindet. (SAMW, 2017).

Schlussfolgerungen

Nicht nur im Rahmen der allgemeinen Suizidprävention, sondern auch im Zuge der zunehmenden Liberalisierung der Gesetze zur Sterbehilfe und dem erleichterten

Zugang zu assistiertem Suizid auch für nicht terminal Kranke, stellt sich die Frage, welche Optionen psychiatrische Fachpersonen Menschen bieten können, die aufgrund einer schweren und chronischen psychischen Störung eine sehr geringe Lebensqualität haben und die ihr Leben aufgrund ihres großen Leidens als nicht mehr lebenswert erachten. Palliative Ansätze könnten gerade in solchen Fällen eine Alternative zu aggressiven und ineffektiven Interventionen mit kurativer Intention darstellen und Autonomie stärkend sowie Selbstwert und Würde erhaltend wirken. Ein klarer Fokus auf die Lebensqualität und ein individuell an die Werte und Ziele der Patienten angepasster Behandlungsplan könnte umgekehrt dazu führen, dass seitens der Patienten weniger Frustration und Hilflosigkeit entsteht.

Es bleibt offen, inwiefern Palliative Care künftig Einzug in die psychiatrische Praxis findet. Eine schweizer Studie zeigt, dass sich eine Mehrheit der befragten Fachärztinnen für Psychiatrie und Psychotherapie offen gegenüber einer Integration von palliativen Ansätzen in die Psychiatrie und ebenfalls eine Mehrheit sieht bei gewissen schwerst psychisch erkrankten Patientinnen die Indikation für Palliative Care als gegeben an (Trachsel et al., n.d.). Wie genau solche Interventionen aussehen sollten und welche Patientengruppen mit welchen psychischen Störungen von Palliative Care besonders profitieren könnten, muss jedoch noch ausgearbeitet werden. Dabei wird es von besonderer Wichtigkeit sein, ein solches Konzept zusammen mit Patientinnen und Angehörigen zu entwickeln. Keinesfalls sollten palliative Ansätze in der Psychiatrie Hoffnungslosigkeit suggerieren oder stigmatisierend wirken. Prinzipien der Palliative Care sollten auch parallel zu kurativen Ansätzen berücksichtigt werden können und eine Alternative für diejenigen Patienten bieten, denen das traditionelle psychiatrische Versorgungssystem nicht gerecht werden kann.

Palliative Sedation on the Grounds of Intolerable Psychological Suffering and its Implications for Refractory Mental Disorders

Article accepted for publication in Boethica Forum

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Abstract

Palliative sedation is a widely accepted medical practice in end-of-life care when goals shift from prolonging life toward primarily providing comfort care and quality of life. Although widespread, the practice remains controversial, particularly where non-physical symptoms are decisive for its application. The present article explores the problematic entanglement of closeness to death and intolerable suffering and the questionable distinction between physical and non-physical symptoms leading to intolerable suffering. Discussion has recently begun around the potential role of palliative approaches for treatment-refractory mental disorders, and euthanasia and physician-assisted dying on the basis of treatment-refractory mental disorders is now a reality in several European countries. In this context, if it is accepted that intolerable suffering can result from both physical and non-physical symptoms, there is a weighty argument in favor of palliative sedation for the relief of intolerable suffering from treatment-refractory mental disorders.

Keywords. Palliative sedation, terminal sedation, treatment-refractory mental disorder, palliative care, intolerable suffering, decision-making capacity

Concept of Palliative Sedation and Traditional Indications

Palliative sedation is a widely accepted medical procedure in end-of-life care when the goals of care shift from a focus on prolonging life toward primarily providing comfort care and quality of life (Gurschick, Mayer, & Hanson, 2015; Veterans Health Administration National Ethics Committee, 2007). Although palliative sedation is a far-reaching intervention that not only reduces the patients' suffering but may sometimes extend beyond that (depending on the depth of sedation) to *every* conscious experience, there is seemingly wide consensus that palliative sedation is an ethically acceptable intervention to relieve intolerable suffering in the dying patient that cannot be otherwise alleviated (Veterans Health Administration National Ethics Committee, 2007). Despite wide agreement on the justifiability of palliative sedation in terminally ill patients, however, palliative sedation remains a controversial practice, particularly where non-physical symptoms are of decisive importance (Bruce & Boston, 2011).

Additionally, there is a striking fuzziness of definition regarding terminology. Terms for palliative sedation sometimes (wrongly) used interchangeably include *sedation to unconsciousness* (Levine, 2008)*, continuous deep sedation* (Levine, 2008)*,* and *terminal sedation* (Battin, 2008; Levine, 2008). The term *terminal sedation* is misleading in that it suggests intentional life-shortening (Cassell & Rich, 2010), with connotations of inducing death. It seems important to counter that palliative sedation is primarily intended to relieve or palliate intolerable suffering that cannot be treated otherwise (Gurschick et al., 2015); fostering death is not a primary goal. Continuous deep sedation can therefore be justified ethically by the doctrine of double effect (McIntyre, 2011)6/13/19 2:41:00 PM: following this reasoning, death as an unintended consequence remains ethically unproblematic (Boyle, 2004). Because hastening death is not the primary goal of palliative sedation other than in cases of misuse—what was sometimes called "slow euthanasia" (Broeckaert, 2011)—the term *continuous* deep *palliative sedation* is therefore more appropriate than *terminal sedation*. However, there is a risk that some physicians abuse palliative sedation to hasten death. This form of "hidden" intention for euthanasia is highly problematic from an ethical perspective, but is not a subject of this paper. Other risks of palliative sedation involve medical risks such as aspiration, pneumonia, problems related to prolonged bed rest, alterations in hemodynamic state, problems with artificial nutrition, paradoxical agitation, and of course, the loss of the ability to interact (Khader, 2015).

There is more or less consensus among experts of palliative sedation that the depth of sedation should be induced in proportion to the severity of suffering the patients experience, i.e. consciousness should only be reduced to the level necessary to control the suffering (Cherny & Radbruch, 2009; Graeff & Dean, 2007; Lo & Rubenfeld, 2005). De Graeff and Dean (2007) suggest three levels of palliative sedation: (1) mild: patients are awake but the level of consciousness is lowered to somnolence; (2) intermediate: patients are asleep but can be woken if needed; and (3) deep: patients are unconscious and in an unresponsive comatose state.

In this article, we attempt to demonstrate that closeness to death is an unsuitable criterion for determining the appropriateness of palliative sedation, and that the distinction between physical and non-physical symptoms (hereinafter psychological/existential suffering) in the context of palliative sedation can be reasonably challenged. We further discuss the implications arising for non-terminal, non-somatic illnesses, including some treatment-refractory mental disorders, in light of the current debate surrounding palliative care approaches and euthanasia or assisted dying for those patients. Furthermore, if palliative sedation is justified on the basis of intolerable suffering, even if the suffering is primarily of existential or psychological nature, this constitutes an argument in favor of (mild and intermediate forms of) palliative sedation for patients with treatment refractory mental disorders.

The Questionable Relevance of Closeness to Death with Regard to Palliative Sedation

In 2008, the Council on Ethical and Judicial Affairs of the American Medical Association decided that palliative sedation should only be considered in the final stages of terminal illness when death can reasonably be expected within the next few hours or days or, at longest, within two weeks (Levine, 2008). Their report argued that palliative sedation is disproportionate for patients with a life expectancy of longer than two weeks because continued life without consciousness in a form of induced coma is purposeless and therefore ethically unacceptable (Levine, 2008). This proposal raises some problems: Aside from the reality of high prognostic uncertainty for even the most critically ill patients, the conflation of intolerable suffering and proximity to death is problematic. By narrowing down the concept of palliative sedation to continuous deep sedation (as implied by the report), the distinction between euthanasia and palliative sedation is blurred and the important concept of proportionality ultimately jeopardized (Claessens, Menten,

Schotsmans, & Broeckaert, 2008). We hold that palliative sedation should not be equated with continuous deep sedation and that there are different appropriate levels and durations of palliative sedation depending on the condition of the patient (see section on "The potential role of palliative sedation for treatment-refractory mental disorders" below).

A further problematic issue is the definition of *intolerable suffering*. We hold that intolerable suffering is related but not necessarily bound to closeness to death. It follows that intolerable suffering as the main prerequisite in deciding for or against palliative sedation and simultaneously denying access to palliative sedation to anyone unlikely to die within the next 14 days (but suffering intolerably) discriminates unfairly against patients with an uncertain or non-terminal prognosis. As Delbeke has put it, "[…] it seems strange to allow access to adequate pain management only to dying patients. […] Every patient has a right to adequate pain and symptom management and it should not be restricted to those with a limited life expectation" (Delbeke, 2013, p. 11).

Defining Intolerable Suffering

While exact prognosis raises difficulties, attempts to define intolerable suffering are no easier; how the notion of intolerable suffering is to be defined and the patient's role in its determination remains contested (Boston, Bruce, & Schreiber, 2011; Schildmann & Schildmann, 2014). These definitional issues are especially relevant because while palliative sedation for the alleviation of intolerable *physical* symptoms is widely accepted, it remains controversial whether treatment-refractory *psychological* or *existential* symptoms with no physical component are sufficient to legitimize palliative sedation. It has been argued that intersubjective elements should be taken into account when assessing whether a patient's suffering is intolerable (e.g., what other individuals would deem intolerable in a similar situation) (Berghmans, Widdershoven, & Widdershoven-Heerding, 2013). However, suffering is ultimately a subjective and private experience that can only be appraised by the patient himself (Cassell, 1998), and individuals differ in what 'intolerable suffering' means to them (Dees et al., 2013; Weide, Onwuteaka-Philipsen, & Wal, 2005). It is undisputed, however, that some psychological or existential symptoms can be refractory, including anxiety, depression, and existential suffering (Cherny & Radbruch, 2009). Making palliative sedation unavailable to these patients is to underestimate psychological or existential suffering as less severe than physical suffering. If intolerable suffering is a key criterion, it should not matter what symptoms underlie that suffering—physical, psychological, or existential. As one of the

most influential contributors on the subject of suffering, Eric Cassell wrote that "[s]uffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it" (Cassell, 1998, p. 639). In the same way, it can be argued that in exceptional cases, palliative sedation may be appropriate not only in cases of physical suffering but also for treatment-refractory psychological or existential suffering, including such states as anxiety and depression (Morita, 2004). A further distinction is sometimes drawn between psychological and existential suffering, as when the Council on Ethical and Judicial Affairs of the American Medical Association stated that "[s]evere psychological distress may also warrant palliative sedation to unconsciousness when potentially treatable mental health conditions have been excluded" (Levine, 2008, p. 4). However, the Council proposed to deny access to palliative sedation for treatment-refractory *existential suffering* "as the experience of agony and distress that results from living in an unbearable state of existence including […] death anxiety, isolation, and loss of control" (Levine, 2008, p. 4).

The above argument for distinguishing between psychological suffering and existential suffering in the context of palliative sedation is invalid for the same reason that it is unsustainable to differentiate between physical and psychological suffering. In this regard, it is appropriate to recall the following words from Cassell and Rich:

> When a source of distress, like pain, produces suffering, it is the suffering that becomes the central distress not the pain. It is not valid to make a distinction between suffering whose source may be physical, such as pain, and suffering coming from the threat to the integrity of the person from the very nature of the person's existence. […] It is no longer valid to make a medical distinction between the body and the mind or the person and the mind. The mind-body dichotomy goes back to antiquity, but is perhaps best known in the form described by Rene Descartes, where the body is part of nature and the material world, and the mind is the place of the soul and part of the spiritual world of God. The dichotomy has been discredited for more than a century but is persistent. For medicine and science persons are of a piece, whatever happens to one part happens to all and whatever takes place in the whole person has an impact on every single part. There is no such thing as a pain or nausea, vomiting, or dyspnea that solely occurs in the

> body without having an impact on the conscious person. (Cassell & Rich, 2010, p. 436)

In other words, it is of no consequence what kind of symptom leads to the treatment-refractory suffering—physical, psychological, or existential—and conceptual delimitation is absent (Boston et al., 2011) or appears incidental. Accordingly, the American Academy of Hospice and Palliative Medicine and other organizations rightly draw no such distinction in their palliative sedation policies (American Academy of Hospice and Palliative Medicine. "Statement on palliative sedation," 2013).

If we accept that psychological or existential suffering can be intolerable in certain cases, the question of palliative sedation on the sole basis of psychological or existential suffering and/or treatment-refractory mental disorders—that is, without additional physical suffering—is just a step away. There is evidence that palliative sedation for some non-physical symptoms is not uncommon (Morita, 2004; Muller-Busch, Andres, & Jehser, 2003; Van Deijck et al., 2015) but we know of no conceptual or empirical study addressing palliative sedation on the grounds of treatment-refractory mental disorders. However, discussion has recently begun around palliative care approaches in this context (Berk et al., 2012, 2008; Lopez et al., 2009; Trachsel et al., 2016b).

Palliative Approaches in the Context of Treatment-Refractory Mental Disorders

It is an inconvenient reality that some patients will, despite best efforts, develop *treatment-refractory mental disorders* such as treatment-refractory major depressive disorder, chronic schizophrenia, or severe and enduring anorexia nervosa. For some of these patients, no treatment has proved effective, including last-resort approaches such as electro-convulsive therapy or ketamine infusions (Andrade, 2017; Lima et al., 2013). Although hope is an important ingredient of mental health care, it sometimes reaches its limit and may result in demoralizing and frustrating cycles of ineffective treatment (Cassell & Rich, 2010). Patients with such treatment-refractory mental disorders are often exposed to aggressive or off-label treatments with unfavorable risk-benefit balances (Berk et al., 2008). Along with several other scholars, we have suggested that palliative care approaches might be considered in the context of exceptional cases of treatment-refractory mental disorders (Berk et al., 2008; Lopez et al., 2009; Trachsel et al., 2016b). This arises when a person's suffering cannot be otherwise alleviated and when all applicable and evidence-based psychopharmacological and psychotherapeutic treatment options with primarily curative intent are exhausted and have proved ineffective. We

believe that palliative care approaches may offer a complementary alternative when treating treatment-refractory mental disorders, improving quality of life for patients and their families by preventing or relieving suffering through harm reduction and circumvention of burdensome and ineffective interventions (Trachsel et al., 2016b). This alternative is driven by a palliative mindset that focuses on short-term quality of life, giving less weight to long-term consequences. So, for example, sedating drugs such as benzodiazepines may be considered less problematic because less emphasis is placed on long-term addiction risk. Besides such relatively mild forms of palliative sedation, there exist stronger forms like sedation to unconsciousness. The various forms of palliative sedation, their appropriateness and justifiability for patients with treatment-refractory mental disorders will be discussed in the next section.

The Potential Role of Palliative Sedation for Treatment-Refractory Mental Disorders

To our knowledge, palliative sedation in the context of treatment-refractory mental disorders has not been discussed in the literature to date. We are aware of only a few case studies discussing the justifiability of initiating palliative care for treatment-refractory mental disorders at the patient's request, possibly including (but not explicitly mentioning) palliative sedation (Lopez et al., 2009; Wang, 2015). Additionally, euthanasia and/or assisted suicide on the basis of mental disorder is now legal in several European countries and is likely to become more established in the near future. Hypothetically, it seems not too farfetched that this group of patients will request deep continuous sedation as an appropriate means of alleviating their suffering as a potential alternative to euthanasia or assisted dying. As elaborated earlier, it can be argued that intolerable suffering may arise from physical or psychological/existential symptoms, or both. While this line of reasoning potentially justifies a request for assisted dying (Schuklenk & van de Vathorst, 2015a), it can also be deployed when discussing palliative sedation for the alleviation of intolerable suffering from symptoms of an underlying treatment-refractory mental disorder without the intention to die. In addition, the prevailing presumption that certain mental disorders are indicative of a lack of decision-making capacity – i.e. automatically render a person incompetent – is persistent but wrong; there is evidence that although impaired decision-making capacity is common, many patients with mental disorders retain capacity (Okai et al., 2007). As for other kinds of diseases, for persons with treatment-refractory mental disorders, the appropriate level

of sedation would have to be chosen and healthcare professionals need to make sure that "the patient is not sedated too lightly (the patient's experience of suffering must be taken away), or too heavily (as warranted by the degree of severity of the symptoms)" (Sterckx, Raus, & Mortier, 2013, p. 35). This stepwise model was named proportionate palliative sedation (PPS) in contrast to palliative sedation to unconsciousness (PSU) (Holahan, Carroll, Gonzalez, & Quill, 2013).

Based on the different levels of sedation mentioned in the introduction section, palliative sedation must not always be permanent and deep but can be temporary/intermittent and in various depths. For treatment-refractory mental disorders, temporary/intermittent either mild (level 1) or intermediate sedation (level 2) seem appropriate. These levels would also allow to completely interrupt the palliative sedation when the patient improves (Materstvedt & Bosshard, 2009).

Some authors argue that patients with psychological or existential suffering often get into a downward spiral of mutually reinforcing symptoms such as fear, sleeplessness, and fatigue which can sometimes be breached by intermittent palliative sedation allowing the patients to regain some energy (Cherny & Radbruch, 2009; Graeff & Dean, 2007). It is conceivable that similar effects occur in patients suffering from treatment-refractory mental disorders. Finally, if sedation is administered with the hope of some therapeutic effect, however, it remains questionable whether the term palliative is suitable to describe the intervention.

Conclusion

In the wake of recent discussion around the role of palliative care approaches for treatment-refractory mental disorders, the role of palliative sedation in this context must be critically evaluated. If it is acknowledged that (a) the term palliative sedation includes mild and intermediate forms of sedation; (b) that proximity to death is (at the least) a controversial criterion for determining the appropriateness of palliative sedation and (c) palliative sedation is justified on the basis of intolerable suffering, even if the suffering is primarily of existential or psychological nature, this constitutes an argument in favor of palliative sedation for patients with treatment refractory mental disorders. In the present article, we don't argue for continuous deep sedation for patients with SPMI but only for intermittent palliative sedation on a mild or intermediate level. Also these forms of sedation can be palliative; palliative sedation must not always be permanent and deep but can be temporary/intermittent and in various depths. Nevertheless, continuous deep

sedation for patients with SPMI is a difficult ethical issue which should be further discussed in the future.

The ambiguity of definitions surrounding psychological or existential suffering must therefore be acknowledged and addressed. Future empirical studies should investigate whether palliative sedation is a clinically relevant, feasible, and beneficent approach to alleviating intolerable suffering among those with treatment-refractory mental disorders that cannot be alleviated by other means. Equally, it seems crucial to develop adequate safeguards and validated guidelines to prevent misuse and to protect this vulnerable group of patients.

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Conflicts of Interest

The authors declare that they have no conflicts of interest with regard to the content of this article.

Summary of Main Findings: Suitability of Palliative Care Approaches

Paper 1

The goals of this paper were:

- to describe which goals of care the responding psychiatrists view as more important than others;
- to provide insight on the conceptualization and associations with SPMI;
    - Are these patients considered to be in a *terminal stage* of their disease?
    - Is a curative framework sometimes considered futile?
- to explore the suitability of palliative care approaches in this context.
    - Do the respondents view palliative care approaches as suitable in the treatment of SPMI patients?

The main finding of the survey among psychiatrists is that palliative care approaches are indicated for certain SPMI. The reduction of suffering was rated the most important goal in the treatment of this patient group. Impeding suicide, on the other hand, was considered an important or very important goal by about 65 percent of all respondents, while no more than 10 percent found curing the illness to be an important aim in the treatment of SPMI. These results clearly underline the parallels between palliative care approaches – where quality of life and reduction of suffering are guiding principles – and psychiatric care for chronically ill patients (Trachsel et al., n.d.). Furthermore, the results challenge the curative framework that frequently guides treatment decisions even in patients that have a very low chance of significant clinical improvement (Trachsel et al., n.d.), raising questions regarding the guiding normative frameworks in the care of SPMI patients. With regard to the case vignettes, respondents equally prioritized quality of life over life prolongation: A vast majority would be comfortable with reducing life expectancy in order to maintain or enhance quality of life. It is in line with these assumptions that most responding psychiatrists believe that in some cases, further curative interventions can be *futile* and that palliative care approaches might be indicated. At the same time, there are limited alternative possibilities for SPMI patients (Trachsel et al., n.d.). Accepting that some SPMI can be terminal and that additional treatment interventions may sometimes be futile, as well as that the main goal in these patients is the relief of suffering, constitutes an *ethical* argument for the development of palliative care approaches.

Paper 2

The goal of this chapter was:

- to describe the concept of palliative care approaches in the care for patients with SPMI.

In this book chapter, we summarize the discourse surrounding palliative care (PC) approaches in the context of SPMI and discuss the concept of medical futility in psychiatry. We conclude that an integration of PC approaches is important. This is particularly the case in countries where (medical) aid in dying (M)AID is a legal option for psychiatric patients. PC approaches may be a feasible alternative option between aggressive but ineffective interventions on one hand, and (M)AID on the other hand. An important aspect will be to include the patients' and families' perspective.

Paper 3

The goals of this paper were:

- to explore the role of palliative sedation in the context of intolerable suffering based on non-physical symptoms;
- to discuss possible ethical implications for SPMI.

The findings from the survey study discussed above provided a good starting point for the theoretical discussion of specific palliative care interventions and their possible use in the context of SPMI. In the light of a special issue of *Bioethica Forum – Swiss Journal of Biomedical Ethics* on the topic of palliative sedation (PS), we have explored how closeness to death and unbearable suffering present suitable decisive criteria for the initiation of PS. We have argued that proximity to death as a criterion for initiation of PS is problematic. On the one hand, there is high prognostic uncertainty regarding remaining life expectancy even for the most critically ill patients. On the other hand, intolerable suffering is not necessarily bound to closeness to death.

Although the considerations remain on a largely theoretical level, it can be argued that if it is accepted that intolerable suffering can result from non-physical symptoms and that closeness to death is a problematic criterion for initiation of palliative sedation, there is a weighty argument in favor of palliative sedation in the context of SPMI. It should be noted that these considerations remain on a largely theoretical level, and may have limited clinical relevance. Yet, it seems worthwhile to critically evaluate the role of palliative

interventions such as palliative sedation, particularly in the light of increasing access of SPMI patients to (M)AID.

| Section II: (Medical) Assistance in Dying

Attitudes towards Assisted Suicide Requests in the Context of Severe and Persistent Mental Illness: A Survey of Psychiatrists in Switzerland

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Abstract

Objective. Switzerland is among the few countries worldwide where a request for assisted suicide (AS) can be granted on the basis of a primary psychiatric diagnosis. Psychiatrists play an increasingly important role in this regard, especially when the request for AS arises in the context of suffering caused by severe and persistent mental illness (SPMI). The objective of the survey was to assess general attitudes among psychiatrists in Switzerland regarding AS requests from patients with SPMI.

Methods. In a cross-sectional survey of 1311 German-speaking psychiatrists in Switzerland, participants were asked about their attitude to AS for patients with SPMI, based on three case vignettes of patients diagnosed with anorexia nervosa, treatment-refractory depression, or severe persistent schizophrenia.

Results. From a final sample of 457 psychiatrists (a response rate of 34.9%) whose mean age was 57.8 years, 48.6% of respondents did not support access to AS for persons diagnosed with SPMI; 21.2% were neutral, and 29.3% indicated some degree of support for access. In relation to the case vignettes, a slightly higher percentage of respondents supported the patient's wish to seek AS: 35.4% for those diagnosed with anorexia nervosa; 32.1% for those diagnosed with depression, and 31.4% for those diagnosed with schizophrenia.

Significance of results. While a majority of the responding psychiatrists did not support AS for SPMI patients, about a third would have supported the wishes of patients in the case vignettes. In light of the increasing number of psychiatric patients seeking AS and the continuing liberalization of AS practices, it is important to understand and take account of psychiatrists' perspectives.

Introduction

Assisted suicide[3] (AS) is now legal in some countries in Europe, in certain U.S. states, in Canada and Colombia, and, from 2019, in the Australian state of Victoria (Dyer, White, & Rada, 2015; Emanuel, Onwuteaka-Philipsen, Urwin, & Cohen, 2016). Traditionally, AS has evolved as a medical intervention, performed by physicians and confined to the terminally ill as a means of preventing unnecessary suffering and to respect patient autonomy. In Western societies, there is wide support for AS among both the public and medical professionals (Emanuel et al., 2016), but the degree of support is strongly dependent on the patient group. Specifically, surveys have shown that physicians, including psychiatrists, are generally more reluctant if the request for AS is based on suffering that relates to mental illness as compared to suffering as a consequence of physical illness (Rousseau, Turner, Chochinov, Enns, & Sareen, 2017; Bolt, Snijdewind, Willems, Heide, & Onwuteaka-Philipsen, 2015; Brauer et al., 2015; Kouwenhoven et al., 2013). AS on the basis of a mental illness is legal in only a few jurisdictions and remains highly controversial (Miller & Appelbaum, 2018; Vandenberghe, 2018; Appelbaum, 2016; S. Kim & Lemmens, 2016; Schuklenk & van de Vathorst, 2015b). However, the number of persons granted access to AS for a psychiatric disorder is increasing. In the Netherlands, 13 cases were reported in 2011, increasing to 60 in 2016 and 83 in 2017 (Regional euthanasia review committees, 2017). In the absence of a reporting system in Switzerland, there is a lack of information about cases of psychiatric AS. However, cases of AS are known to have increased since 2008, with an absolute increase in non-terminal patients seeking AS (Steck et al., 2018). The Swiss model differs significantly from other approaches in a number of ways (see Box 1). Internationally, Switzerland is the only country whose legal framework requires neither a terminal (somatic) condition for patients requesting AS nor a specific role for physicians in the request process. Instead, the physician's involvement is confined to assessing decision-making capacity (DMC) and prescribing the lethal drug, with no further legal

[3] In the course of legalization and depending on prevailing concepts, established terms differ; these include *assisted suicide* and *(medically) assisted dying*. While aware of the controversy surrounding these different terms, the term *assisted suicide* is used here because it is commonplace in Switzerland.

regulations governing access and procedure (Gamondi, Borasio, Oliver, Preston, & Sheila Payne, 2017; Ziegler & Bosshard, 2007). In practice, non-governmental "right-to-die" organizations (RTDOs) evaluate, coordinate, and respond to AS requests (Ziegler, 2009; Ziegler & Bosshard, 2007). RTDOs define internal guidelines that specify necessary preconditions and procedural requirements, including whether requests can be made on the basis of suffering related to mental illness (Ziegler & Bosshard, 2007). Criticism notwithstanding, the Swiss model has been described as de-medicalizing AS and resolving some ethical dilemmas commonly faced by medical professionals (Ziegler, 2009). Until now, AS in Switzerland has ostensibly been treated as a political and public concern rather than a medical one. Nevertheless, many of Switzerland's hospitals, nursing homes, hospices, and other institutions involved in the care of seriously ill patients encounter AS requests. Some institutions have begun to develop their own internal guidelines for refusing or allowing AS in their wards (Harding, 2005; Tuffs, 2007). In cases where suffering caused by mental illness is the primary reason for requesting AS, psychiatrists and other mental health care staff are likely to be involved. In Switzerland, only one study to date has explored physicians' support for AS in different medical scenarios, including dementia and mental illness that is refractory, chronic and severe (Brauer et al., 2015). That study was commissioned by the Swiss Academy of Medical Sciences (SAMS) to obtain an overview of physicians' views on AS and to inform new medical-ethical guidelines for "Management of dying and death" (Swiss Academy of Medical Sciences (SAMS), 2018). In the survey, 28% of all responding physicians supported the principle of AS while 22% were clearly opposed. About 40% of respondents believed that physicians should be allowed to perform AS (Brauer et al., 2015). While the survey sheds some light on the attitudes of physicians practicing in Switzerland, the low response rate of 34.9% and the wide variation of respondents from different professional specialties serve to limit the generalizability of the results. In addition, SAMS has recently revised its guidelines on *physician-assisted* suicide. The new guidelines propose circumstances in which physician-assisted suicide may be ethically justifiable but notably refrain from including terminal illness as a criterion for AS (Swiss Academy of Medical Sciences (SAMS), 2018). The present study explores psychiatrists' general attitudes to AS in the context of SPMI, with reference to three clinical scenarios presented as case vignettes.

Table 5

The Swiss Model

Regulated by the Swiss Criminal Code, Article 115 on "Inciting and assisting suicide"

"Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty"

Features

- no further regulations regarding content (e.g. eligibility criteria for AS) or formalities (e.g. procedural measures)
- no formal role for physicians

Right-to-die organizations

While everyone can legally assist someone in dying/suicide (unless guided by selfish motives), in practice, non-governmental right-to-die organizations evaluate, coordinate and respond to requests. They formulate their own guidelines and access to AS based on their personnel's assessment of a specific case.

Role of doctors

- assessment of decision-making capacity (need not necessarily be psychiatrists)
- prescription of the lethal drug
- Medical-ethical guidelines (not binding until incorporated into the Code of the Swiss Medical Association FMH) of the Swiss Academy of Medical Sciences set out ethical principles and offer guidance for physicians and nurses

Research Questions

To determine the attitudes of physicians with specialist training in psychiatry to AS requests from patients with SPMI and, specifically, their willingness to support a patient's decision to make such a request, two research questions were asked: (1) whether German-speaking psychiatrists in Switzerland support the possibility of AS in patients with SPMI in general, and (2) whether they would be willing to play an active role in AS. Additionally, the participants were asked to evaluate three case vignettes: a patient with severe and enduring anorexia (vignette 1); a patient diagnosed with treatment-resistant depression (vignette 2); and a patient suffering from severe persistent schizophrenia (vignette 3). The third research question asked (3) whether their support would differ for the patients in the three case vignettes.

Methods

The quantitative cross-sectional survey was conducted in cooperation with the Swiss Society for Psychiatry and Psychotherapy (SSPP), based on a previously reported protocol (Trachsel et al., n.d.). The study fell outside the scope of the Swiss Human Research Act (HRA) (Swiss Federal Council, 2014) because no personal data related to human diseases or the structure or function of the human body were collected. However, the study was assessed according to the *Checklist for the ethical evaluation of empirical studies that do not need mandatory authorization (CEBES)*; No. CEBES-2016-04. Participants' identities were anonymized, and the study was non-interventional in nature. All participants received a copy of the survey by mail with an enclosed prepaid return envelope, followed four weeks later by a postcard reminder.

Sample

The total sample (n = 1311) included all German-speaking members of the Swiss Society of Psychiatry and Psychotherapy (SSPP), corresponding to approximately 30% of psychiatrists in Switzerland. Data were collected during the period February–March 2016.

Survey and Case Vignettes

This article reports 5 of 42 items targeting different aspects of care for SPMI patients, with particular reference to the suitability of palliative care approaches for this group of patients (Trachsel et al., n.d.). (See Table 4 for all survey items.) The two subsets of items (palliative care approaches and assisted suicide in the context of SPMI) are purposefully reported separately, as they relate to two distinct topics. Participants were asked to respond to the statements on a 7-point Likert scale, ranging from *completely disagree* (-3) to *completely agree* (+3), with mid-point *neutral* (0). The case vignettes have previously been published in other contexts (Trachsel et al., 2015; Brenner et al., 1990; Baweja & Singareddy, 2013) and were adapted to suit the purpose and format of the survey. (See Table 3 for the case vignettes.) Participants also had the option to make additional comments in a 'General Comments' section; any such comments were translated into English.

Statistical Analysis

Arithmetic means were calculated for age and work experience, and descriptive statistics (percentages) were calculated for gender, as well as for the Likert scale items. IBM SPSS Statistics 24 was used to perform the analysis.

Patient and Public Involvement

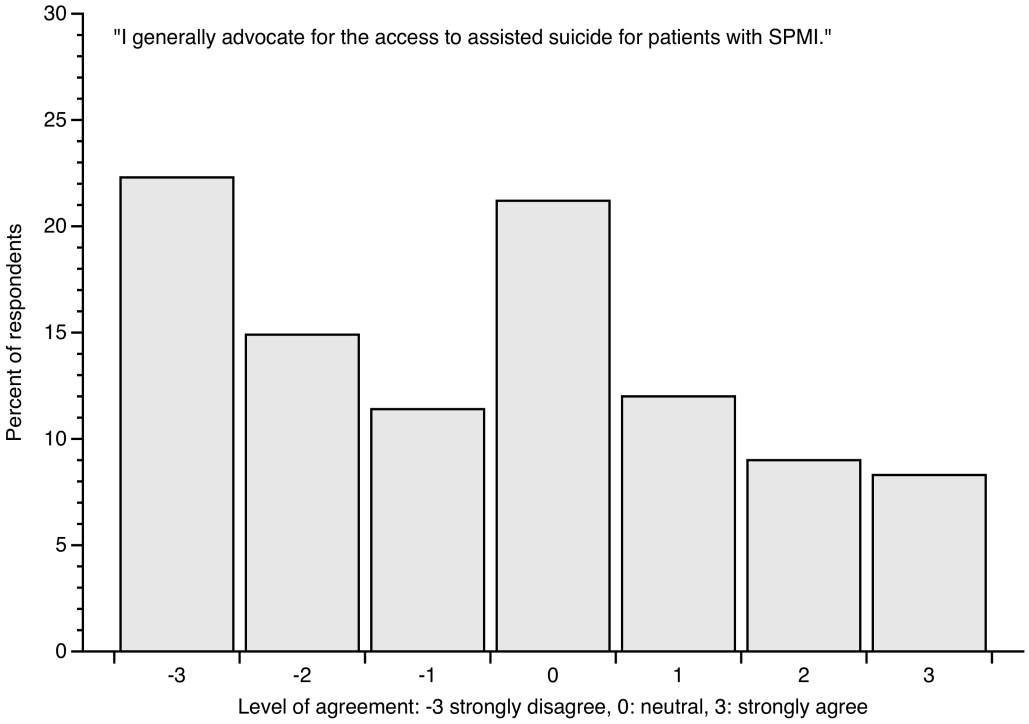
Because the goal of the study was to investigate the attitudes of psychiatrists, there was no direct patient involvement in the survey's development. However, the survey design was informed by studies involving patients (as in the case vignettes). An advisory board of experts from psychiatry, psychology, and palliative care was involved in all steps of the study, and further research from the patient perspective is planned.

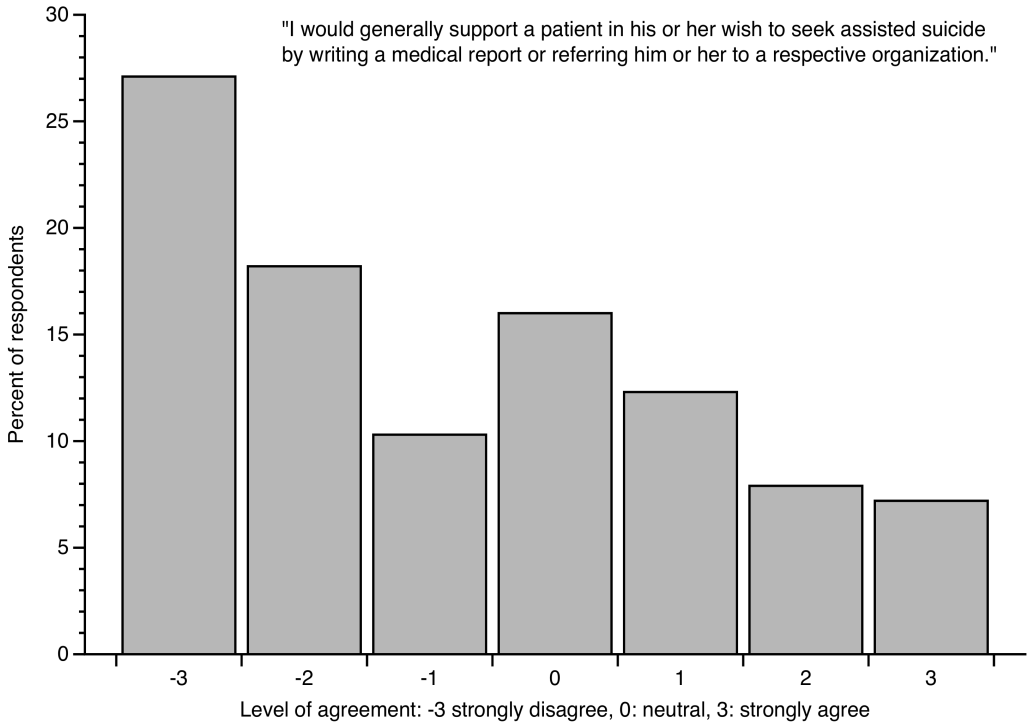
Results

Sample characteristics. The response rate was 34.9% (457 of 1311 recipients). Respondents' mean age was 57.8 years; 37% were female, and 4.2% did not indicate their gender. The gender distribution reflected the total sample of active SSPP members (62.9% male vs. 37.1% female). Mean work experience was 27.7 years (missing $n = 23$).

Attitudes towards assisted suicide on the basis of severe and persistent mental illness.

Figures 3 and 4





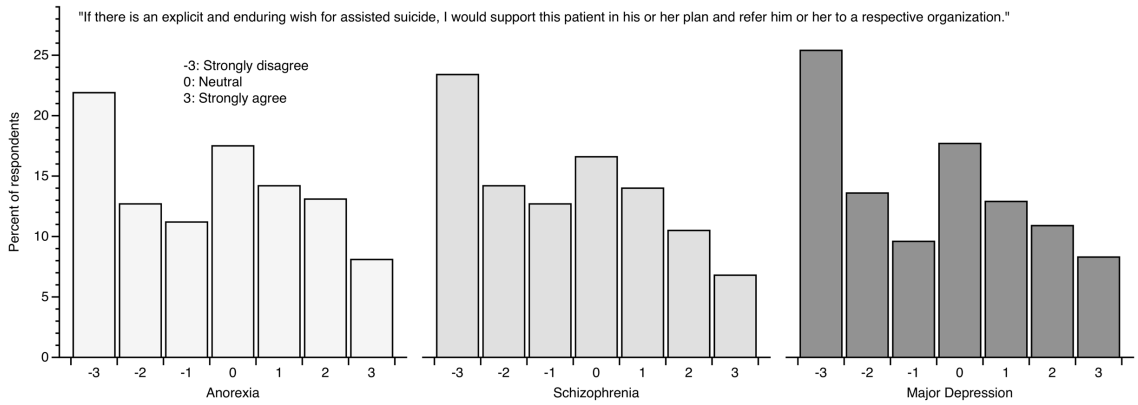
Note. Psychiatrists' attitudes on access to and support for assisted suicide on the basis of a mental disorder.

Overall, 48.6% of respondents stated that they did not generally support access to AS for persons diagnosed with SPMI (-1, -2 or -3, where -3 designates *strongly disagree*). A further 29.3% stated that they supported access to AS to some degree (1, 2 or 3, where 3 designates *strongly agree*) while 21.2% remained neutral (rating 0). (Missing $n = 4$ or 0.9%.) There were no differences in age and work experience between those who remained neutral and the rest. For detailed results see Figures 3 and 4.

In total, 55.6% of respondents would not support an AS request from a patient with SPMI by writing a psychiatric report or referring them to an RTDO (-1, -2, -3, where -3 designates *strongly disagree*). A further 27.4% would provide support (1, 2 or 3, where 3 designates *strongly agree*) while 16.0% remained neutral. (Missing $n = 5$ or 1.1%.)

Responses to vignettes.

Figure 5



Note. Views of survey respondents by case vignette.

In total, 45.8% of respondents would not support the explicit and enduring wish for AS of the patient described in case vignette 1 by referring her to a relevant organization (-1, -2 or -3, where -3 designates *strongly disagree*). In contrast, 35.4% would provide support (1, 2 or 3, where 3 designates *strongly agree*) while 17.5% remained neutral. (Missing n = 6 or 1.3%.)

About half (50.3%) of respondents would not support the explicit and enduring wish for AS of the patient described in case vignette 2 by referring him to a relevant organization. A further 31.3% would provide support while 16.6% remained neutral. (Missing n = 8 or 1.8%).

Finally, 48.6% of respondents would not support the explicit and enduring wish for AS of the patient described in case vignette 3 by referring him to a relevant organization. However, 32.1% would provide support, and 17.7% remained neutral. (Missing n = 7 or 1.5%). For detailed results see Figure 5.

Comments section. Anecdotes recorded in the General Comments section of the survey indicated that psychiatrists may experience conflicts of interest when confronted with an AS request. One respondent wrote: “As a psychiatrist, I would help to abolish my own profession if I were to support suicide.” Another respondent stated:

> I would only dare to make an assessment if I had known the patient over a longer period of time but not on the basis of a single cross-sectional consultation. Generally, I do not support suicide in my position as a treating physician,

regardless of my personal stance. Reason: I believe that my own personal judgement is dangerous because the patient initially consulted me to improve his life. However, the patient has the possibility of being assisted to commit suicide independent of me.

Discussion

To our knowledge, this is the first study to systematically assess the attitudes of psychiatrists working in Switzerland to the practice of AS for psychiatric patients. In light of recent developments surrounding AS and psychiatry, this quantitative study makes an important contribution to current discourse.

General support for AS in patients with SPMI. While almost half of the respondents opposed access to AS for patients with SPMI, more than a fifth were neutral, and 29.3% agreed that patients with SPMI should have access to AS. These results correspond to the findings of another study of Swiss physicians of all subspecialties, in which about 32% of respondents considered AS to be justifiable for SPMI (Brauer et al., 2015). That study also revealed that acceptance of AS for psychiatric patients is no higher or lower among psychiatrists than among medical providers in general (Brauer et al., 2015). Similarly, a survey of Canadian psychiatrists' attitudes to AS in the context of a primary psychiatric diagnosis found that 29.4% were supportive, with general support for AS in some circumstances (e.g., terminal illness) at 72% (Rousseau et al., 2017). In light of current scholarly debate and the multiple objections raised by many experienced clinicians, the level of support reported here for AS in patients with SPMI is significant, as is the high percentage of neutrals (ranging from 16% to 21.2% for different items). Importantly, there were no differences in age and gender between neutrals and the rest. Although interpretation of a *neutral* rating is speculative, it may reflect the ambivalence and role conflict currently experienced by psychiatrists in relation to AS (Miller & Appelbaum, 2018); indeed, this ambivalence was stressed by some respondents in the General Comments section. As several of those comments noted, the practice of AS is often thought to conflict with the high priority psychiatry assigns to suicide prevention (Hewitt, 2013; Schuklenk & van de Vathorst, 2015a). This is curious, since AS and unassisted suicide have traditionally been viewed as distinct phenomena; only recently (and solely within psychiatry) have scholars begun to discuss a possible overlap. Specifically, it has been argued that psychiatric AS is difficult to distinguish from suicide

because of certain shared characteristics, and this may ultimately affect societal commitment to suicide prevention (S. Y. H. Kim, Conwell, & Caine, 2018).

Willingness to provide active support for psychiatric patients seeking AS. Of the responding psychiatrists, 27.4% would actively support SPMI patients in the event of a concrete AS request—for instance, by writing a psychiatric evaluation or referring the patient to an RTDO. Willingness to provide support was even higher for the specific case vignettes (35.4% for the patient with anorexia nervosa; 31.4% for the patient with schizophrenia; and 32.1% for the patient with depression). These findings contrast with a previous qualitative study of palliative care physicians in Switzerland, which found that establishing contact with the RTDOs was clearly perceived to be the patient's responsibility (Gamondi et al., 2017).

Lack of variation within diagnoses. There is evidence that the source of a patient's suffering can determine the physician's willingness to grant an AS request, and that for a majority of physicians, physical symptoms are a prerequisite for "unbearable" suffering (Bolt et al., 2015; Van Tol, Rietjens, & van der Heide, 2010; Rietjens, van Tol, Schermer, & van der Heide, 2009). To our knowledge, no study to date has investigated the variation of physician support for different *psychiatric* diagnoses. In the present case, there was only a small degree of variation in support for the three different patients in the case vignettes. This is somewhat surprising, as their prognosis varied, especially in relation to fatal outcomes. While all three patients had an increased risk of death (Ivbijaro, 2017; Laursen, Nordentoft, & Mortensen, 2014), those with anorexia nervosa are known to have the highest mortality rate of all mental illnesses (Arcelus et al., 2011). Additionally, the case patient suffering from major depressive disorder exhibited concrete suicidal intent, making a potential fatal outcome more likely. Interestingly, this did not significantly influence the participating psychiatrists' willingness to support the depressed patient in seeking AS, with 32.1% supporting access to some degree. The lack of variation in diagnoses may be linked to general underlying attitudes to AS in psychiatric patients—that is, the participating psychiatrists either generally approved or generally disapproved of the practice as a whole.

Strengths and Limitations

The present study has several strengths. It is the first to specifically assess the largely unexplored attitudes of psychiatrists to AS in psychiatric patients in Switzerland

using quantitative methods. Additionally, the inclusion of distinct case vignettes provides a more differentiated picture of psychiatrists' support for AS in patients with SPMI.

The study also has several limitations. The non-response rate raises the possibility of non-response bias, although respondents' age and gender correspond to the total population of SSPP members. We did not explore other possible confounding variables such as sector (e.g., private practice or hospital; adult or geriatric psychiatry) or personal experience of AS. As only about 50% of all psychiatrists are members of the SSPP, there is a risk of sampling bias; additionally, only German-speaking psychiatrists were recruited for this survey, and it is known that attitudes to end-of-life practices differ across language regions in Switzerland (Fischer et al., 2006). Nevertheless, our results correspond with those from a recent survey of Swiss physicians in all three language regions (Italian, French, and German), in which 33% of all respondents tended to support AS for patients with SPMI (Brauer et al., 2015). Finally, it is important to stress that Likert scale items shed no light on underlying concepts that may have influenced the psychiatrists' responses. Additionally, the decision to include a "neutral" midpoint made interpretation more difficult. A neutral response might indicate indecision or ambivalence; on the other hand, respondents may have chosen the mid-point because they were not sufficiently concerned or engaged. The decision to offer this neutral option was deliberate, as we considered it important not to force respondents to take a side in order to avoid possible frustration, especially in relation to such a controversial subject. In any event, it seems unlikely that respondents would not be sufficiently concerned to adopt a clear position, given that AS is a reality of increasing importance in Switzerland.

Future Directions and Implications for Clinical Practice

In the few countries where AS on the basis of a primary psychiatric diagnosis is legal, the number of patients seeking AS continues to increase (Dierickx, Deliens, Cohen, & Chambaere, 2017; S. Kim & Lemmens, 2016). Given the ongoing global liberalization of AS practices and the likelihood of psychiatrists' involvement—especially if the suffering relates to a mental illness—it is important to understand and take account of psychiatrists' perspectives. More research (especially qualitative research) is needed in order to systematically assess the reasons underpinning psychiatrists' views. That knowledge should in turn inform psychiatrists' formal training in responding to requests and end-of-life issues in general, particularly where AS is a legal option for psychiatric patients.

In Switzerland, there is a particular urgency to develop a systematic approach to AS in order to adequately safeguard vulnerable patients with SPMI. The authors contend that psychiatrists who openly endorse the option of AS for some SPMI patients have an obligation to remain critical and to accept professional responsibility. To ensure adequate safeguards for SPMI patients, it is essential that psychiatrists are involved in the evaluation process (e.g., assessment of decision-making capacity and possible alternatives). Those psychiatrists who generally refuse access of AS for SPMI must remain committed to the care of any of their patients contemplating AS. To abandon any patient on the basis of divergent moral beliefs is unethical and ultimately harmful to chronically suicidal patients. Refusing to openly discuss the option of AS with SPMI patients in a value-neutral environment is clearly counterproductive in caring for suicidal SPMI patients.

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Competing Interests of All Authors

None.

Authors' Contribution/Acknowledgements

MAH and MT constructed and conducted the survey; MAH analyzed the data and drafted the manuscript. All authors were involved in the study's conception and design, interpretation of the data, critical revision of the article and final approval of the version submitted for publication.

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Letter to the Editor

Letter published in JAMA Psychiatry

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In their recent article in *JAMA Psychiatry*, Olié and Courtet (2016) took the report by Kim and colleagues on euthanasia or assisted suicide (EAS) of psychiatric patients in the Netherlands as an occasion to highlight the challenges surrounding the legalization of EAS in patients with a psychiatric illness (Scott Kim, Vries, & Peteet, 2016). The present contribution comments on their propositions.

First, Olié and Courtet mention the option of palliative care for terminally ill patients as a possible alternative to EAS (Olié E & Courtet P, 2016). We believe that the achievements of contemporary palliative care indicate relevance beyond the context of terminal somatic illness, for the significant group of people suffering from severe persistent mental illness (SPMI). For this group of patients, we advocate a shift towards patient-oriented palliative care, centered on the ethical principle of patient self-determination. Given its focus on empowering people with mental illness, the recovery movement is already heading in this direction (Jacobson & Greenley, 2001). However, some of those with SPMI may have a long history of failed functional recovery. Their suffering may be unbearable and their therapeutic options exhausted. In such specific cases, a reorientation of care goals toward symptom relief as the main focus of care—possibly without modifying the course of the disease—may be a legitimate option.

Second, the authors mention the possibility of EAS evaluations in the interests of suicide prevention. Although suicide prevention has a long history in psychiatry, there are potential risks in focusing mainly or exclusively on impeding suicide without taking account of the risks of overly aggressive care or even coercion. The severe side effects and interactions of polypharmacy, as well as the patient's (and doctor's) possible sense of failure, may result in an even poorer quality of life for the patient (Berk et al., 2012). We agree with Yager[5] that hyper-interventionism (especially against the patient's wishes) and treatment excesses are not supportable; and that even patients with partially impaired decision-making capacity retain some capacity to make prudent decisions in respect of their long-term desires.

We are fully aware of the controversy surrounding futility and palliative care for patients suffering from SPMI (Berk et al., 2012; Yager, 2015). First and foremost, however, we would observe that a palliative approach in psychiatry does not mean giving up on a patient but rather involves redefining the goals of care. This entails accepting the reality that mental illness can be fatal. With improvements in the quality of care, there might be fewer requests for EAS.

Disclosure

This work was supported by the Palliative Care Research funding program of the Swiss Academy of Medical Sciences; and the Stanley Thomas Johnson Foundation. The views expressed in this letter are those of the authors and not necessarily those of the funder. The funding body in no way influenced the authors in writing the manuscript. The authors declare to have no competing interests.

Summary of Main Findings: (Medical) Assistance in Dying

Paper 4

The goals of this paper were:

- to provide insight into the attitudes of the responding psychiatrists regarding the practice of (M)AID in the context of SPMI;
- to explore their willingness to support patients in their wish to die in the specific case vignettes.

Data from the survey indicate that only a minority (less than 30 percent) of the respondents advocate for access to (M)AID on the sole basis of suffering from a mental disorder. More than a fifth of all respondents remained neutral (rating '0' on the Likert scale), and slightly less than half of the respondents do not generally advocate for access. The willingness to support patients in seeking (M)AID was even less strong: More than 55 percent would not support a patient, e.g., by writing a psychiatric report. In the case vignettes, similar figures were obtained. Support was strongest for (M)AID for the patient suffering from severe and enduring anorexia nervosa (SEAN) and weakest for the patient with treatment-resistant depression (TRD) (35.4 percent and 32.1 percent respectively). Most notably, there was considerable variance in the answer pattern, with heavy use of the neutral middle-point ('0'). Support for (M)AID in this sample corresponds with a study that questioned physicians of all subspecialties in Switzerland (Brauer et al., 2015), and a study of psychiatrists from Canada, where (M)AID is not a legal option (Rousseau et al., 2017). In view of the finding that most respondents in the same survey believed some forms of SPMI to be terminal and additional curative interventions as sometimes futile (Trachsel et al., n.d.), limited support of the concept of (M)AID raises some questions regarding remaining alternative options for this group of patients.

Paper 5

In this letter, we replied to a previously published article by Olié and Courtet (2016). In their comment, Olé and Courtet highlight current challenges surrounding the legalization of (M)AID in the context of mental disorders based on data regarding (M)AID from the Netherlands (Scott Kim et al., 2016). We argue that contemporary palliative care has relevance beyond the context of terminal somatic illness and advocate for a shift toward patient-oriented palliative care for SPMI patients whose therapeutic options are exhausted. We criticize hyper-interventionism in such patients and stress that

chronically mentally ill patients may remain some capacity to make decisions regarding their long-term wishes. To improve quality of care for the most severely ill, we argue, a redefinition of goals of care may be of great value.

| GENERAL DISCUSSION

Structure and Aim

In this final chapter, I first critically evaluate the methodological approach used in the survey study. In a second step, I take up the findings from the papers and integrate them into a broader ethical debate. I conclude from my original research that the topic of death and dying is not sufficiently addressed within mental health care and subsequently reflect on the reasons why.

A focus lies on the concept of *autonomy* and its special position within psychiatry and mental health. Specifically, I address the problem of overriding patient autonomy in the context of SPMI. I argue that autonomy in patients with severe and persistent mental illness (SPMI) is a more contested issue than in patients with physical illness, despite lacking evidence of significant differences regarding incapacity. Furthermore, I hypothesize that the professional identity of psychiatrists contributes to a paternalistic approach regarding SPMI patients, particularly if they refuse treatment and are at increased risk of dying. These factors, I suggest, contribute to the lack of discussion of end-of-life options such as palliative care (PC) and (M)AID in psychiatry. The thesis concludes with clinical implications resulting from my considerations. Furthermore, I present potential research domains suitable for deepening the understanding of patient needs in the context of life-threatening forms of SPMI.

Critical Appraisal of the Survey Conducted Within This PhD Project

The empirical part of this PhD project was concerned with the development and conducting of a survey distributed among German-speaking members of the Swiss Society of Psychiatry and Psychotherapy (SSPP). The results from this survey served as the basis of subsequent conceptual considerations. While the survey was a first step toward the understanding of psychiatrists' attitudes regarding goals of care for SPMI patients, PC approaches, and (M)AID, it certainly had several limitations.

Survey: Limited Generalizability

The results from the survey are of descriptive nature. Their generalizability to the entire psychiatric community in Switzerland is further confined by several factors:

First, the nonresponse was beyond 65%. While this nonresponse rate is not particularly low for physicians (Cunningham et al., 2015), it is still notable, particularly in the context of a rather sensitive and complex topic such as PC and (M)AID in the

context of SPMI. However, it is important to note here that no statistical calculations were performed, reducing the impact of a potential response bias.

Second, the study did not include French- and Italian-speaking psychiatrists. The language region is known to be a strong determinant of differences in attitudes, particularly toward end-of-life decisions (Fischer et al., 2006) and medical end-of life practices (Hurst, Zellweger, Bosshard, & Bopp, 2018).

Third, Likert scale items do not allow profound insights or assumptions as to *why* the respondents answered in a certain way. To gather insight into the diverse concepts and thought processes that have led to the detected answer patterns, a more differentiated quantitative or a qualitative approach is inevitable. The great utilization of the comments' section further suggests the respondents' need to further clarify their answers.

Lack of Specificity of the Conceptual Framework

As a consequence of the broad definition of palliative care, it has been argued by reviewers and respondents alike that almost every psychiatric intervention is:

> An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO, 2015)

They further argue that the definitional fuzziness is hampering interpretation of the results from the survey. Therefore, critics have argued, what respondents have understood of PC approaches, remains unclear. While this certainly limits the conclusions that can be drawn from the survey results, it is unlikely that respondents have interpreted palliative care as including just *any* psychiatric intervention with no explicit curative intend (e.g. short time management of general distress in anorexia nervosa patients with benzodiazepines). Considering the still widespread view of palliative care as being applied mainly in an end-of-life context, a very broad interpretation of the term seems unlikely.

Ultimately, the main aim of the empirical research project marking the onset of this PhD project was its *stepping stone* function. With the limited generalizability in mind, the goal of the original research from the previous sections was to better describe the normative framework psychiatrists use when thinking about SPMI and its treatment. With these limitations in mind, some results from the survey remain striking and give cause to

critically scrutinize the status quo in psychiatric practice, which is attempted in the following sections.

A Broader Perspective on the Findings

In the first paper section, the main finding is that the questioned psychiatrists believe that the focus for some SPMI patients should lie on *relief of suffering* and that sometimes, a *curative* framework is inappropriate in the care for SPMI. Additionally, a striking majority of respondents agree with describing the course of some SPMI as *terminal*. Based on this initial work, I argue in the theoretical contributions that PC inspired principles, focusing on relief of suffering without major therapeutic intent, should guide the care for SPMI patients with low chance of recovery and enhanced risk of dying prematurely, and that psychiatry faces a strong ethical argument for investing in the development of such approaches.

In the second section, I report on the lacking consensus regarding (M)AID among survey respondents and stress the importance that the psychiatric community further engages with the topic of (M)AID. Accepting the social reality of (M)AID for SPMI patients and systematically addressing questions that arise with (M)AID is of paramount importance in order to adequately safeguard for SPMI patients.

Subsequently, I now explore in more detail why topics such as death and dying, PC, and (M)AID are not explicitly subject of discussion within the psychiatric community. I thereby focus on issues surrounding the concept of *autonomy and competency* in the context of SPMI, as well as on the professional identity of psychiatrists potentially complicating the discourse. Based on the recognition that there is a blind spot in mental health care regarding end-of-life options, I begin with a brief reflection on the topic of death and dying within mental health care.

Death and Dying and Psychiatry

Terms with a connotation of death and dying, such as *end-stage*, *terminal*, or *palliative* are, with some exceptions (Campbell & Aulisio, 2012; O'Neill, Crowther, & Sampson, 1994; Sommer & Raj, 2017), rarely used in psychiatric language. Considering that mental disorders rank among the most substantial causes of death worldwide, with an estimate of 14.3 percent of all deaths being attributable to mental disorders (Walker et al., 2015), the lack of attention to end-of-life care is difficult to understand. Research usually focuses on the *seriously physically ill patient* with a comorbid psychiatric

disorder, rather than on the SPMI patient coping with serious physical illness (McGrath & Forrester, 2006). As a result, efforts to engage SPMI patients in end-of-life discussions and palliative care are only made in tertiary care, or on cancer and palliative units (Woods, Willison, Kington, & Gavin, 2008). There, SPMI patients are at high risk of receiving treatment not in line with their values and preferences (Shalev, Brewster, Arbuckle, & Levenson, 2017). Despite evidence that SPMI patients are willing and able to voice their end-of-life preferences (Elie et al., 2017), their potential end-of-life care needs on the side of mental health institutions are largely unknown. The field of palliative care for individuals is thus wide open and a call for collaboration between mental health institutions and palliative care has been made (Woods et al., 2008).

Survey respondents in this project, for their part, have not been averse to considering some forms of SPMI as *terminal* and a significant proportion of respondents indicated that they would not be surprised if the patients described in the case vignettes *died* within the next 6 months (more than 80 percent for the patients diagnosed with SEAN and TRD respectively, and still 45 percent of all respondents for the patient diagnosed with schizophrenia). The *surprise question* – "Would I be surprised if this patient died in the next 6/12 months?" – has been widely used in somatic medicine to identify patients who are at risk of death and would possibly benefit from end-of-life care and palliative care approaches (White et al., 2017). These answer patterns contrast with the predominant framework for treatment of mental disorders. They are also in sharp contrast with one of the core arguments against making (M)AID available to persons with mental disorders: Within this specific debate, there is general consensus that mental disorders are, in general, not terminal (Simpson, 2018).

Whether or not one conceptualizes some SPMI as terminal, the expansion of (M)AID to patients with mental disorders poses an unprecedented challenge to psychiatry. The topic has caused increasing disputes and divisions among professional organizations on both an international and national level. Recently, the Swiss Medical Association (FMH) has voted against incorporating the revised SAMS medical-ethical guidelines on death and dying into their own professional code of conduct (Vögeli, 2018). The only controversial issue in the said guidelines was a brief section on prerequisites for ethically acceptable *physician* involvement in assisted suicide (Swiss Academy of Medical Sciences (SAMS), 2018, p. 23). In the revised guidelines, the *closeness to death* criterion has been replaced with the criterion of *unbearable suffering*. The FMH considers

the criterion of unbearable suffering as too vague and expansive. This lack of consensus regarding the legal possibility and societal reality of psychiatric (M)AID is also reflected in our survey. About half of all respondents do not support access to (M)AID for SPMI patients, more than a fifth remain neutral and about a third supports access to (M)AID for SPMI patients to some degree.

In the light of these findings, I contend that the lack of a scientifically driven debate about (M)AID within psychiatry as a potential end-of-life option for SPMI patients is ultimately harming patients. One potential consequence of the refusal to address the (legal) reality of (M)AID is that right-to-die associations (RTDOs) may increasingly become a port of call for SPMI patients who encounter the taboo status of the practice of (M)AID in psychiatry.

In the following section, I will look at potential obstacles that prevent mental health institutions in general, and clinicians in particular, from adopting end-of-life approaches and engaging in a discourse regarding (M)AID.

Personal Autonomy and Responsibility to Treat

As indicated in the introduction, one of the key ethical issues in caring for mentally ill patients lies in how to balance *personal autonomy* with the *responsibility to treat.* In contemporary medical care, patients usually direct their care and decide about the tolerable level of invasiveness of the care interventions offered to them. This premise of modern medicine has been proven to be more challenging in the context of mental illness. Frequently, societal interests in protecting others and the interest in the patients' health interfere with the personal autonomy of patients (Sjöstrand & Helgesson, 2008), and a paternalist perspective is known to be prevalent in mental health institutions (e.g., Veikko Pelto-Piri, Engstörm, & Engström, 2013). Furthermore, many mentally ill patients' autonomy may indeed be affected by their disorder, demanding careful evaluation and ethically challenging clinical decision-making.

If there is little likelihood for the patients to ever improve significantly, as is the case for some SPMI patients, clinicians are faced with even more complex ethical dilemma. Overriding a patient's wish becomes increasingly difficult to justify if the potential benefit of a forced treatment intervention is highly unlikely (for further elaboration, see section on professional fallibility on p. 93). Yet, as was reflected in our survey, proceeding against (competent) patients' wishes by coercive measures is a clinical reality. (See Table 6.)

Table 6

Coercive Measures and Patient Autonomy

In this case, I would accept a temporary decrease in quality of life due to coercive measures

	disagree (%)	*agree (%)*
Anorexia nervosa	62.1	25.6
Major depression	47	39.4
Schizophrenia	44.2	41.1

In this case, I would not proceed against the patients' wishes

	disagree (%)	*agree (%)*
Anorexia nervosa	21.2	66.3
Major depression	34.1	48.4
Schizophrenia	36.8	44.2

Note. From unpublished results by the author.

Even though a majority of respondents would refrain from applying coercive measures, a significant percentage of respondents would act against the patients' articulated wishes, despite the patients presumed competence (see case vignette 1 on p. 18: "*Two experts have declared that the patient has decision-making capacity to refuse further treatment, with consequent risk of dying*"). For the SEAN patient, for example, this would entail compulsory admission and, potentially, force-feeding, since the patient stated that she would "rather die than undergo further treatment" and "doesn't want to be forced into eating anymore" (again, see case vignette 1). This unpublished result inevitably raises the question *why* a substantial number of respondents feel comfortable in disregarding the patients' autonomy in such circumstances.

One option is that they *doubt* the experts' assessment that the patients in the case vignettes are truly competent in making a (potentially life-limiting) decision. Another option is that the respondents' professional obligations and their self-understanding as psychiatrists *sufficiently justifies* overriding the patients' wishes. Indeed, there is a predominant assumption that experts have the competence to balance the four main ethical principles ("autonomy," "beneficence," "non-maleficence," and "justice") in *the best interest* of the patient (Beauchamp & Childress, 2001; Kendall, 2014). Notwithstanding the underlying rationale, proceeding against the patients' wishes, for example by coercive measures, in these cases is extremely problematic from both a legal and ethical point of view.

As highlighted above, the right to refuse medical treatment is at the core of personal autonomy. Yet, beneficent coercion remains highly prevalent in mental health institutions, and particularly for SPMI patients with a low probability of improvement and at risk of dying. In the next two sections, I discuss potential preconceptions regarding autonomy in SPMI patients and how these relate to patients with severe physical illness. Moreover, I reflect on the professional identity of psychiatrists and the deriving professional duties that may prevent clinicians from discussing end-of-life options with their patients. I argue that both aspects deserve close scrutiny in order to honor the principle of patient self-determination in the context of SPMI.

Severe and Persistent Mental Illness and Autonomy

As has been discussed in the introduction, preconceptions about the competence of SPMI patients to make valid end-of-life decisions have been raised particularly in the context of medical futility decisions in SEAN patients or access to (M)AID for patients with treatment-resistant depression. Although there is a general consensus in modern mental healthcare that some SPMI patients retain their competence to make far-reaching decisions, the main worry seems to be rooted in the complexity of distinguishing between competent and incompetent individuals. This process is inevitably error-prone and the consequences potentially far-reaching and irreversible. This risk of false positives for many opponents of (M)AID justifies an in-principle exclusion of SPMI patients (Schuklenk & van de Vathorst, 2015b).

Interestingly, such concerns regarding capacity within end-of-life scenarios are less prevalent in the context of severely physically ill patients, despite evidence suggesting that decision-making capacity for those patients might not differ significantly from those of psychiatric patients: A comparative, cross sectional comparison between patients admitted to a psychiatric hospital and a medical in-patients at a general hospital rendered no differences in prevalence of incapacity (Owen et al., 2013). Moreover, there is evidence that decisional capacity in terminally physically ill patients might actually be severely impaired (Kolva, Rosenfeld, Brescia, & Comfort, 2014). Yet, this issue has not gained much attention up to this point. Additionally, in the context of decision-making *for* a certain intervention, concerns about capacity are typically less prominently discussed. Lapid et al. (2013), for example, conclude in their study that severely depressed patients can achieve high scores on the MacCAT-T, a clinical tool to assess patients' capacities to make treatment decisions (Grisso, Appelbaum, & Hill-Fotouhi, 1997),

indicating that they likely had the capacity to decide about treatment with ECT (Lapid et al., 2003). Lima et al (2013) and Miyamoto, Jarskog, & Fleischhacker (2014) entirely refrain from discussing the potential risk of impaired decision-making capacity in their reviews on ECT therapy use in adolescents with SPMI (Lima et al., 2013; Miyamoto, Jarskog, & Fleischhacker, 2014). This phenomenon and the fact that the bars are per default set higher for decision-making capacity whenever decisions are made by mentally versus physically ill patients stands in need of further discussion.

That said, it is important to stress that certainly, in many cases, clinicians are obliged to override an articulated patient wish. Patients with acute mania, psychosis, or suicidal intent obviously lack the capacity to make their own treatment decisions, and paternalistic intervention to protect them from harming themselves until their autonomy is restored, is not only justified, but also ethically desirable. When it comes to patients who have prolonged forms of SPMI, such as the patients described in the case vignettes, the presumption of permanently impaired capacity dissolving their autonomy is much more difficult to substantiate.

A Brief Note on Professional Fallibility

In this context, relatively little attention has been directed toward the potential *fallibility* of professional knowledge with regard to overriding patient wishes and involuntary treatment. Yet, considering clinical heterogeneity and high prognostic uncertainty associated with many psychiatric disorders, this seems all the more important. The interaction between the degree of uncertainty about a potential benefit of a treatment and the amount of harm done due to paternalistic measures is ethically highly relevant. As mentioned several times above, the more seriously and chronically ill an SPMI patient is, the less likely the benefit of an additional treatment. At the same time, due to the high stakes (life at risk), patients are more prone to receive the said treatment. To what extent an experimental treatment with a limited chance of success can ethically justify overriding patient autonomy based on the "best interest principle" requires further investigation.

Professional Obligations Justifying Overriding Autonomy

In the following section, I will now address two important professional obligations of psychiatrists: the goal of preserving life and the importance of maintaining hope. I reflect on how these two core obligations may hinder clinicians in dealing with difficult topics arising in their practice.

Preserving life: its special role in psychiatry. As mentioned in the beginning, suicide prevention is of high significance in psychiatry. There is a general understanding that suicide is preventable and that its completion is a failure of the mental health care system (Walter & Pridmore, 2012). In the context of the (M)AID debate, many psychiatrists have stressed the importance of protecting life (Kelly, 2017) and the incompatibility of (M)AID with the "physicians' professional commitment to preserve life and promote health" and "our societal responsibility to prevent suicide and protect and care for people with mental illness" (Miller & Appelbaum, 2018). This general attitude is represented in the findings from our survey study, where a majority refused the concept of (M)AID for SPMI patients, despite accepting that SPMI can be terminal and that in some cases, additional (curative) interventions can be futile.

There is little guidance on how clinicians can work towards suicide prevention and at the same time take the death wish of their (potentially competent) patients seriously. Yet, if psychiatric practice regarding suicidality remains highly restrictive, patients who are seriously considering ending their lives find themselves in the position of having to be not entirely truthful with their clinicians at a time when they most need emotional support (Yager, Ganzini, Nguyen, & Rapp, 2018). Here, palliative care approaches, rather than fostering hopelessness and implying "giving up on a patient," would provide an opportunity for continuing compassionate care despite diverging objectives between patients and clinician. While general guidelines on the topic are lacking, some authors have given general recommendations on how to interact with patients with severe and chronic mental disorders and increased risk of death. Yager (2015), for example, believes that in the treatment of SEAN patients, it is important to maintain connection, relationship and interest, and to offer comfort care. He suggests to avoid judgmental or shaming questions and has no particular therapeutic intent or expectations towards the patient. Furthermore, he stresses that patients should have every chance, at every point in time, to ask for more help, such as active intervention. (Yager, 2015). From both the original work conducted during this PhD project as well as abundant conversations with experienced clinicians on this topic, I conclude that such suggestions have relevance beyond the care for dying SEAN patients. Psychiatrists must be prepared to discuss the difficult topic of (M)AID if brought up by their patients. Responding to a (M)AID request, however, will always be challenging to the patient-doctor relationship. Yet, the treating clinician with an established relationship with the patient, is the

appropriate person to sensitively explore the request without taking it at face value. PC inspired principles such as connectedness, compassion, respect and dignity towards the suffering patients may guide such discussions and similarly ease the moral dilemma between protecting the patient's life and respecting the patients (potentially autonomous) wish to die. I argue that being prepared to listen with empathy does not equal giving up, and that sufficient training is necessary for clinicians to develop this important skill.

Maintaining hope: The last resort. The objection that a palliative terminology (including terms such as *end-stage mental illness*, *futility*, and *palliative care*) will put patients into a passive sick role and therefore minimize the patient's motivation and will has been made (Jäger & Hoff, 2012). In line with this reasoning, assigning SPMI patients to later/end stages of a continuum would suggest hopelessness and ultimately reduce chances of (personal) recovery (Trauer, 2012). Trauer, in his critique of the staging model (including palliative models for later stages of the disorder), has objected: "The potential damage done to the expectations of patients (and their families) by them detecting, rightly or wrongly, that they have been placed into an 'incurable' category, would be most unfortunate and difficult to repair" (Trauer, 2012, p. 172) In a similar manner, policies aiming at harm reduction (e.g., in the context of alcohol or drug dependence) have been criticized as being recovery-hindering by helping patients to "self-harm more safely" (Pearce & Pickard, 2010). Yet, while hope certainly is an important ingredient in mental health care, it remains unclear what effect a (false) promotion of hope has on some SPMI patients with very low chances of recovery. Additionally, there is anecdotal evidence that while patients with little experience with mental healthcare prefer optimistic and confident psychiatrists, longer-term patients who may have experienced treatment failures do not share this preference (Priebe et al., 2017).

Implications in Practice and Future Research Areas

Summary of Ethical Considerations

The disagreement between clinicians and scholars begins with the lack of consensus on the language used to describe the group of patients who are chronically ill and continuously experience symptoms that have a major negative impact on their life. A few years ago, the proposal to adopt the concept of medical futility in psychiatry has briefly sparked discussion among clinicians and ethicists. In this context,

clinicians and ethicists have stressed the potential risk of characterizing patients as *incurably* ill. Specifically, the consequences of categorizing them as palliative or within the end stages of a clinical staging model, some have argued, is harmful and diametrically opposed to the professional duties of psychiatrists: preserving life and maintaining hope. Others, including us, have argued that the current framework is ill suited to benefit the most severely and chronically mentally ill patients. In order to free necessary resources, a discussion must be launched about the needs of this (neglected) patient group and how they can be addressed by mental health care services. An option is the recognition of palliative care approaches as possibly transferable to mental health care services.

Furthermore, I have discussed the reasons I believe contribute to the loud silence regarding death and dying within psychiatry. I argue that preconceptions regarding SPMI patients' autonomy need to be further explored, particularly in view of decision-making in severely mentally versus physically ill patients. Furthermore, I discuss aspects relevant for the professional identity of psychiatrists, and conclude that the normative framework derived from (traditional) professional obligations of psychiatrists clashes with the acceptance that some patients reject intrusive interventions against medical advice, and that some of these patients may autonomously chose death over living with their SPMI. In view of recent developments regarding end-of-life options outside mental health care, I hold that psychiatrists must remain open towards discussing (M)AID with their patients.

Future Research Topics

From the original research as well as the subsequent considerations regarding factors aggravating patient self-determination of SPMI patients, I now aim at suggesting areas of future research.

First, the needs of SPMI patients need to be better explored. Questions guiding qualitative studies may entail: Where have mental health services proven to be helpful for SPMI patients and what has been counterproductive? How are "difficult" topics such as irremediableness and death discussed in psychiatric care? Are there institutional barriers that prevent patients from getting the care they need in later stages of their disease?

Second, a deeper understanding of the framework guiding psychiatrists will be helpful in better addressing their concerns and fears regarding the topic of dying, autonomy and treatment refusal. A deeper understanding of these issues will be crucial in the development of training and guidelines on how to work with (potentially autonomous) SPMI patients considering (M)AID.

Third, the usefulness of palliative approaches, focusing on a redirection of goals in line with clearly defined patient preferences and values, should be explored as a potential alternative in legislations where (M)AID is an option. It needs to be investigated how palliative principles could complement recovery-oriented, patient-centered practice without competing them. Furthermore, research should aim at further defining how palliative care as an integral part of mental health care could look like. Last but not least, it has to be explored whether the term *palliative* indeed is suitable in the context of mental health care, or whether a different terminology (e.g. *supportive care*, as I have previously suggested) are less contested and find better acceptance.

Final Conclusion

As has been demonstrated throughout this thesis, the clinical reality of unremitting mental illness and the social reality of end-of-life options outside the scope of mental health institutions for SPMI patients (i.e. [M]AID) requires that more traditional approaches to treatment, developed for earlier stages of mental illness, undergo a transformation to better fit the needs of those with SPMI. As has been stressed by ourselves and others, the worth of palliative approaches needs to be further explored in this context. Endorsing end-of-life discussions how we understand them does not equal abandoning patients (as has been implied by some scholars within the futility and [M]AID debate), but merely entails a *redirection of goals of care* in line with the patient's own preferences and values. Whether severely mentally ill individuals are capable of deciding about the direction of their treatment, including decisions that potentially reduce remaining life expectancy, needs to be assessed on a case-to-case basis. Above all, it is essential for the treating team to appraise the highly specific and unique circumstances for each SPMI patient when making treatment decisions with the patient.

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